DOCUMENT RESUME

ED 207 283 EC 140 017

AUTHOR Deenan, Vincent Daniel
TITLE Planning Residential and Vocational Services for Mentally Retarded Young Adults: Parents' Choices.
PUB DATE 81
NOTE 114p.; Master's Thesis, University of Illinois at the Medical Center.

EDRS PRICE MF01/PC05 Plus Postage.
DESCRIPTORS Demography; Elementary Secondary Education; *Family Relationship; *Long Range Planning; *Moderate Mental Retardation; *Parent Attitudes; Prediction; Residential Programs; *Severe Mental Retardation; Stress Variables; Vocational Training Centers

ABSTRACT

Indepth interviews were conducted with parents of moderately and severely/profoundly retarded children on the following topics: the nature of the child's retardation, services used or expected to be used, how the current program was chosen, satisfactions and dissatisfactions with these services, and the effect of having a mentally retarded child in the family. Data from the interviews were combined with a review of the literature to formulate a questionnaire completed by 330 parents. Among results were that variables measuring family career and individual life cycle were among the strongest predictors of parents' planning for future residential and vocational services; as predicted by B. Farber's theory of minimal adaptation, parents experiencing more stress individually and in their relationships with their spouses planned for future resiential services more than parents experiencing less stress; family demographics were generally not associated with parents' future plans; and families' involvement in personal and community support networds were statistically significant predictors of parents' planning for residential services. Reasons for backlash against mainstreaming and deinstitutionalization are examined. (CL)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

U.S. DEPARTMENT OF EDUCATION
NATIONAL INSTITUTE OF EDUCATION
EDUCATIONAL RESOURCES INFORMATION
CENTER (ERIC)

This document has been reproduced as received from the person or organization originating it.

Minor changes have been made to improve reproduction quality.

• Points of view or opinions stated in this document do not necessarily represent official NIE position or policy.

ED207283

PLANNING RESIDENTIAL AND VOCATIONAL SERVICES FOR MENTALLY RETARDED YOUNG ADULTS: PARENTS' CHOICES

BY

VINCENT DANIEL KEENAN
B.S.Ed., Northwestern University, 1978

THESIS

Submitted in partial fulfillment of the requirements
for the degree of Master of Science in Public Health
in the Graduate College of the
University of Illinois
at the Medical Center, 1981

Chicago, Illinois

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY

Vincent D. Keenan

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

EC140017

ACKNOWLEDGEMENT

The research reported here was supported from a grant from the Extramural Research and Grants Development Program of the Illinois Department of Mental Health and Developmental Disabilities (Grant #843-02), "Parental choice of services for developmentally disabled children," awarded to Marijean Suelzle, Department of Sociology and Center for Urban Affairs, Northwestern University, as Principal Investigator. I would like to thank Marijean Suelzle for the opportunity to participate in the research on families and her ability to fulfill a variety of roles: mentor, teacher, co-author, and most especially, friend.

The members of my thesis committee, Dr. Louis Rowitz, Chairman, Dr. Gary Albrecht, and Dr. Mimi Rodin provided thoughtful criticism and whole-hearted support of my work. I thank them for their endeavors.

The data on which this report is based were collected and readied for computer analysis by the staff of the Developmental Disabilities Project, including: Charlene Ough, Melody Singleton, David Staats and Jane Taylor. Janet Gans cleaned the raw data, readied it for computer analysis, and did the factor analysis to construct the indices.

Finally, I owe a deep debt of gratitude to the members of my family who provided their supportive assistance--my parents, Anne and Hubert Keenan, my parents-in-law, Dorothy and Louis Mascitti, and my wife, Patricia M. Keenan. Withcut their caring this report would never have been completed.

VDK

TABLE OF CONTENTS

CHAPTER		PAGE
I	LITERATURE REVIEW	1
	A. Introduction	1
	B. Public Health and Mentally Retarded Persons . .	4
	C. Family Careers and Life Cycle Stages	8
	D. Planning Services for Mentally Retarded Persons	25
	E. Normalization	31
	F. Advocacy	37
II	HYPOTHESES AND METHODOLOGY	41
	A. Hypotheses	41
	B. Research Methodology	51
	C. Variables and Methods	63
III	RESULTS	71
IV	DISCUSSION	87
	A. Implications for Theory	88
	B. Implications for Planning Services	92

LIST OF TABLES

TABLE		PAGE
I	SUMMARY OF HYPOTHESES ABOUT THE DIRECTION OF THE PREDICTED ASSOCIATIONS BETWEEN RESIDENTIAL AND VOCATIONAL PLANNING (DEPENDENT VARIABLES) AND FAMILY DEMOGRAPHICS, FAMILY CAREER, COMMUNITY INVOLVEMENT AND ADVOCACY, CHILD'S CHARACTERISTICS, AND EXTENDED FAMILY	42
II	LAKE COUNTY, ILLINOIS, FAMILIES WITH MENTALLY RETARDED CHILDREN 21 YEARS OF AGE AND UNDER--IDENTIFIED, CONSENTING TO PARTICIPATE IN SURVEY, AND RETURNING SURVEY QUESTIONNAIRE	61
III	COMPARISON OF RESPONDENTS' CHARACTERISTICS WITH 1970 CENSUS DATA FOR LAKE COUNTY, ILLINOIS, AND WAUKEGAN POPULATIONS, AND FOR WAUKEGAN BLACK AND SPANISH-LANGUAGE SUBPOPULATIONS	62
IV	MEANS AND STANDARD DEVIATIONS OF VARIABLES	64
V	CORRELATIONS FOR VARIABLES USED IN REGRESSION ANALYSIS FOR ALL RESPONDENTS (ABOVE DIAGONAL, N=330); RESPONDENTS WITH CHILD AT HOME (BELOW DIAGONAL, N=291)	72
VI	CORRELATIONS FOR VARIABLES USED IN REGRESSION ANALYSIS FOR RESPONDENTS WITH MENTALLY RETARDED CHILDREN LIVING AT HOME: RESPONDENTS WITH GRANDPARENT(S) LIVING (ABOVE DIAGONAL, N=248); MARRIED RESPONDENTS (BELOW DIAGONAL, N=253)	73
VII	REGRESSION ANALYSES OF FAMILY AND COMMUNITY VARIABLES ON RESIDENTIAL AND VOCATIONAL PLANNING FOR TOTAL SAMPLE (REPORTED COEFFICIENTS ARE BETA WEIGHTS, N=330)	76
VIII	REGRESSION ANALYSES OF FAMILY, COMMUNITY AND CHILD VARIABLES ON RESIDENTIAL AND VOCATIONAL PLANNING FOR RESPONDENTS WITH CHILDREN AT HOME (REPORTED COEFFICIENTS ARE BETA WEIGHTS, N=291) . . .	78
IX	REGRESSION ANALYSES OF FAMILY, COMMUNITY, AND CHILD VARIABLES ON RESIDENTIAL AND VOCATIONAL PLANNING FOR RESPONDENTS WITH CHILDREN AT HOME AND GRANDPARENT(S) LIVING (REPORTED COEFFICIENTS ARE BETA WEIGHTS, N=248)	79

TABLE		PAGE
X	REGRESSION ANALYSES OF FAMILY, COMMUNITY, AND CHILD VARIABLES ON RESIDENTIAL AND VOCATIONAL PLANNING FOR CURRENTLY MARRIED RESPONDENTS WITH CHILD AT HOME (REPORTED COEFFICIENTS ARE BETA WEIGHTS, N=253)	80
XI	BETA COEFFICIENTS AND R^2's FOR REGRESSION ANALYSES OF FAMILY, COMMUNITY AND CHILD VARIABLES ON RESIDENTIAL AND VOCATIONAL PLANNING TO TEST FAMILY CAREER STAGE AS ALTERNATIVE HYPOTHESES TO CHILD'S CHARACTERISTICS	85

SUMMARY

My thesis explores the relationship between families' adaptations to their mentally retarded children and the manner in which parents plan for future residential and vocational settings. Farber's (1975) theory of minimal family adaptation is tested to see whether family characteristics, such as demographics and family career; child's characteristics, such as severity of the disability, sex and age; and the family's involvement in informal and formal social networks affects parents' planning. A thorough literature review informs the analysis of data gathered from a 57-page mail survey questionnaire of 330 parents of mentally retarded children in Lake County, Illinois, from birth to twenty-one years of age. These children have mental retardation which is probably of an organic basis and would most likely be labeled "trainably mentally retarded" or "severely and profoundly mentally retarded" in the educational system. Children who would be labeled "mildly or educably mentally retarded" are not considered in this report.

The analyses consist of a series of ordinary least squares regression analyses to evaluate the overall contribution of family characteristics, child's characteristics and the family's involvement in social networks to parents' planning for residential and vocational settings. Variables measuring family career and individual life cycle were among the strongest predictors. Support was found for Farber's theory of minimal adaptation within nuclear families and its extension to extended family members was supported. Variables measuring family's involvement in social networks showed that family involvement results

more from an informational need than from a supportive therapeutic need. Discussion of the implications of the findings to theories about families with mentally retarded children and to planning services for mentally retarded adults concludes this report.

CHAPTER I. LITERATURE REVIEW

A. Introduction

Parents' roles are important in the transition to adulthood for mentally retarded persons because these adolescents cannot make the decisions for future vocational and residential options on their own. Therefore, parents must exercise those options for their mentally retarded children. Parents, instead of their children as one might generally expect, are the clients of the service delivery system.

The parents' movement brought about the development of services to mentally retarded persons in the 1950's and 1960's and through the 1970's has been primarily concerned with monitoring the quality of services. The focus of the parents' movement and the resultant services has been on severely mentally retarded persons as opposed to those more mildly afflicted, and on services to children as opposed to adolescents and adults. The services for the more severely handicapped children have been routinized through educational, judicial and legislative processes, so that at the present time a comprehensive service system, coordinated through the schools, is available for three to twenty-one year olds. However, the post-school stage for mentally retarded young adults is not so well coordinated or routinized.

Planning of services on a regional basis for mentally retarded children and adults has begun. In the past, service providers were aware of the services they provided but there was no effort to map out the entire service delivery system. Now consumers, service providers

and funding agencies are combining their efforts in order to list available services and identify gaps in the service delivery system. The gaps in services to mentally retarded adults are many because there are not enough services provided in all the categories of service, and some categories have no service providers at all. Planning the implementation of more comprehensive, well-coordinated services to the mentally retarded young adult population should include all the persons affected by its provision: funding agencies, service providers and clients (where possible) or their representatives.

Parents of mentally retarded children in the past have organized themselves in order for their children to receive a publicly-funded and appropriate education and there is evidence that they are willing to organize themselves for obtaining new services now if they can be properly motivated (Suelzle and Keenan, 1980). Parents are not the only ones with a vested interest in improved and expanded services. Large lobbies of professionals whose bureaucracies depend on the service system (Felicetti, 1975; DeZutter, 1980:3) are eager to see it expand. But, parents have the most important investment because their lives have been deeply affected by the presence of mentally retarded children in their families.

Planners and professionals in the mental retardation field can provide an effective service system through understanding mentally retarded adolescents, their parents, and the ways in which these families lead their lives and make choices for services now and plan for services in the future. Parents are the most important members of the team of professionals providing services to children (Keenan and Suelzle, 1980).

Their direct participation in programs helps children tremendously (Karnes, Zehrbach and Teska, 1977). Their participation in the process of planning services to developmentally disabled young adults and adults will ensure that the most important voices are heard.

The growing interest in planning and implementation of integrated and coordinated service delivery systems for mentally retarded persons (Aiken, et al., 1975:3) is in need of a strong research base from which to move forward. Services need to complement the varying capacities of families to deal with their mentally retarded adult children. Capacities for coping are based upon the strengths and weaknesses of the family as a unit and family members as individuals. A framework of family careers and life-cycle stages can be used as a means of looking at the varying capacities of families to cope with mentally retarded children. Understanding the family ethology will enable planners to incorporate parents' input into service system plans.

There are many similarities among families with mentally retarded adolescents. Parents' roles in these families are different from those families who do not have such children. Families with mentally retarded adolescents have continuing rather than diminishing responsibility for their children's lives (Birenbaum, 1971:64). Parents are responsible for the continuity of services from the school years to adulthood for their mentally retarded young adults but their own lives are changing, too.

It becomes more difficult for parents to exercise this responsibility, because they are aging, their strength and stamina are decreasing, and their developmentally disabled children are now out of

synchronization with family and individual development (Farber, 1975: 252). Mentally retarded adults remaining at home are not in school, therefore have less opportunity for peer contact, and yet they are making more demands on the family at the same time when family development expectations would deem that children would be making less demands.

For mentally retarded adults the community must provide day care, evening and weekend recreation activities, as well as alternative living arrangements and job opportunities (Wing and Olson, 1979:176). Otherwise, the investment in education made earlier will be lost if mentally retarded adults become isolated within the community. Activities designed for children must be present- and future-oriented; present-oriented for educational purposes and future-oriented to answer the question, "Education for what?"

Each of the issues implicit in the foregoing (public health, family careers and life cycle stages, planning, normalization and advocacy) need to be examined in greater detail in order to understand more fully each area's individual influence and all areas' collective interaction.

B. Public Health and Mentally Retarded Persons

Mentally retarded persons represent a significant proportion of the population of the United States and therefore have a significant impact on medical and social service systems and families. Kurtz (1977: 71) using generally accepted estimates of the number of non-institutionalized mentally retarded individuals with the current average family size and a population base of 210 million, concludes that there are 15

to 20 million people in the United States who live with a mentally retarded person. That is, between seven and ten percent of all Americans have daily contact with mentally retarded persons in their families.

From the medical viewpoint, mental retardation is a chronic illness which evolves over time, causing pathologic changes which are fixed and irreversible. Applying the public health model of prevention (Mausner and Bahn, 1974:9-11) to mental retardation shows different kinds of intervention techniques used to prevent retardation from occuring or to eliminate or to ameliorate the effects of retardation. The first level of prevention is primary prevention. Intervention techniques at this level, such as genetic counselling and improved nutrition for pregnant women, are used to prevent the occurrence of mental retardation. Secondary prevention utilizes early detection and prompt treatment either possibly to cure the disease or to slow its progression, prevent complications and limit disability. Treatment of phenylketonuria (PKU) and hypothyroidism, detectable at birth through blood sampling, either prevents or arrests the development of mental retardation depending upon the timing and success of the special diets required. Tertiary prevention consists of limiting the course of the disability and providing rehabilitation, restoring the affected person to a useful, satisfying and self-sufficient role. Tertiary prevention of mental retardation involves medical and educational interventions whose aims are to assist the disabled individual to achieve their maximum possible functioning.

Since the etiology of most mental retardation is unknown, primary and secondary prevention play a much smaller role than tertiary in its prevention. A very large system of educational, vocational and

residential services have arisen to meet the rehabilitative needs of the mentally retarded population. The rehabilitation component of tertiary prevention suggests that the individual be the primary recipient of rehabilitation. Adams (1971:62) however, posits the creation of a rehabilitative environment in order to diminish social disability and dependence. The most important components of this environment are not services directed at specific acute problems, "but at sustaining the individual and responsible adults who support the disabled in the chronic problem situations resulting from the handicap" (Adams, 1971:65).

Due to their lifelong responsibility for their mentally retarded children, parents tend to be the responsible adults in need of sustaining services described by Adams. In order to plan for the provision of these services, the primary tool of public health, epidemiology can be used to measure the number of mentally retarded persons in an identified population by relating the number of cases to a population base. Of two epidemiological measures, incidence (the rate at which new illness occurs) and prevalence (the amount existing at a given point in time in a community), prevalence is more satisfactory because it represents the total number of existing cases of disability at the time the need for services is being measured. Stein and Susser (1975:54) support this argument:

> In long lasting disorders, the main service need flows from the accumulation of cases which is governed by the duration of time over which newly arising disorders remain active. Mental retardation is lifelong. That is, duration equals survival.

Mercer (1973b) describes such a social system epidemiological study which was carried out in Riverside, California.

Abramowicz and Richardson (1975) reviewed twenty-seven community studies of severely mentally retarded children (those with I.Q.'s less than fifty) and found the reliable prevalence data in nineteen of the studies showed a remarkable consistency of approximately four cases per 1000. Since most of the children with I.Q.'s less than fifty have a biological rather than social etiology for their disability, there tends to be no association between severe mental retardation and social class. For mild mental retardation, however, there is a strong association with lower social class. Other reviews of the literature (Farber, 1968:79; Lapouse and Weitzner, 1969; Hurley, 1969; Hansen, Belmont and Stein, 1980) reinforce this finding.

Reviewing the social factors associated with mental retardation Rowitz organized the research into four perspectives that seem to grow out of the epidemiological study of mental retardation. A combination of two of the perspectives forms the basis for the present study (1974:405). "The social epidemiological perspective of Western Europe has been epidemiological but has a strong concern for program planning and evaluation (for example, Kushlick, 1975). . . . The crisis research trend has been concerned with how families cope with their mentally retarded child" (for example, Farber, 1968; Birenbaum, 1971). While epidemiology forms the basis for planning service needs, studying families with mentally retarded individuals allows for understanding its social implications. Parents make the decisions concerning the family member with mental retardation, based upon their ability to cope with the disabled individual, familial and community support, and their knowledge of community resources. Combining the two types of information gleaned

from the research provides a solid basis for planning services that are consumer-oriented, meeting the needs of the total population to be served.

C. Family Careers and Life Cycle Stages

The philosophical idea of human development includes the notions of family careers and life cycle stages. The developmental orientation focuses on families and individuals as changing entities within a developing environmental framework. Whereas the medical model focuses on mentally retarded individuals and their families as sick persons, the developmental model views mentally retarded individuals as persons with a wide range of abilities and disabilities and their families as having varying capacities to cope with members having some disabilities. In the medical model mentally retarded persons and their families are treated as patients or clients to whom treatment processes are prescribed and rendered in order to eliminate or control the disorders. In the developmental model the disabilities are seen as life-long limitations that will affect mentally retarded persons and families differently at various times in the individuals' life cycles and in the families' careers. Educational interventions at different points seek to ameliorate the effects of the disabilities in order to enhance the maximum feasible functioning of the families and their disabled members in society.

The developmental approach is but one of many conceptual frameworks used to study the family. Hill and Hansen (1960:307) have traced the history of the developmental approach to family study from a variety

of disciplines. From rural sociologists it borrowed concepts of stages of the family career. From child psychologists and human development specialists came the concepts of needs and tasks. From the sociologists engaged in work in the professions it incorporated the concept of the family as a convergence of intercontingent careers. From the sociologists using the structural-functionalist and interactionist approaches were borrowed the concepts of age and sex roles, and the many concepts of the family as a system of interacting actors.

The idea of life cycle stages is at least as old as the ancient Greek civilization. Plato in The Republic (1974) outlines different stages in the educational careers of young Greek men, beginning with early childhood and culminating in the attainment of the position of philosopher-ruler in the late thirties. In more modern times Erikson (1963) forged Freud's theory of personality development in childhood and Jung's conception of the entire life cycle into the "eight ages of man." The field of developmental psychology, where much of the work on life cycle stages now takes place, combines several different disciplines: psychology, sociology, biology, philosophy and literature, to name a few.

While distinct enough from each other to have spawned different approaches to the study of individuals and families, they are conceptually alike in a number of ways which affords their combination to study the effect of developmentally disabled adolescents on their families. The interaction of the adolescents' life cycle stages and the families' careers will be explored by first defining what is meant by each and then discussing how they interact in the transition to

adulthood for mentally retarded adolescents.

Family Career. The family can be defined as the mediator between the individual and society. As the basic social institution, the family interprets society's rules of conduct for its members. Yet the term, family, subsumes a wide range of diversity in structure, function, values, and lifestyles. The services that the family provides for its members, other than the affectional, have been transferred to outside agencies with the advent of industrialization and urbanization (Winch, 1971).

The family remains intact by having its members fulfill various family tasks and willingly continue in the family group. Its greatest capacity is its ability to counter or amplify changes occurring inside and outside the family unit. "The events that lead to family formation, the addition of members--their passage through the educational system and their eventual departure--all require the family to change existing interaction patterns to accommodate new personnel, to fill the gaps left by those who have gone, or to meet the changing demands of its members and of society" (Aldous, 1978:46). It is the predictable changes in the life course of the family which form the bases for stages in the family career.

A stage is a division in the family career that is distinctive enough from periods that come before and after it to make it a separate stage. Aldous (1978:81-86) discusses the varying ways that researchers have chosen to divide the family career and how the different roles of the family members tend to be qualitatively different at each stage of

the family career. She uses Duvall and Hill's (1948) stage classification as the basis for the analysis of nuclear family careers in the following stages (Aldous, 1978:86):

Stage I	Newly Established Couple
Stage II	Childbearing
Stage III	Families with School Children
Stage IV	Families with Secondary School Children
Stage V	Families with Young Adults
Stage VI	Families in the Middle Years
Stage VII	Aging Families

Those stages most pertinent to this study are IV, V, and VI--families with secondary school children, families with young adults, and families in the middle years. In stage IV, adolescents are beginning to press for more independence in anticipation of leaving their family of orientation. While first described as a period of storm and stress by Hall (1904) and often characterized as such by others, the "generation gap" between parents and adolescents has been shown to be less stormy and stressful where parents anticipate their adolescents' entry into adult roles and actually prepare them for it. Parental relinquishing of control and adolescent acquisition of responsibility do not, however, proceed at a steady rate in all areas. Parents and adolescents maintain stable arrangements in some areas in order to facilitate the changes that take place in other areas (Aldous, 1978:264). The attainment of adolescence for children in the nuclear family coincides with a time of relative economic need by parents who are in their forties or early fifties. Except in the case of high level professionals, managers and sales occupations, average earnings for families have peaked at an earlier time period, therefore earnings are at that time somewhat less. As a consequence, these families run a risk of deterioration in their

standard of living unless additional income is obtained (Oppenheimer, 1974).

In stage V, parents and their young adult children try to reform relationships in order to relate to each other as adults rather than as parents and children (Levinson, et al., 1978:23). Parents experience a chance to reformulate their relationship with their spouse as their parental responsibilities decrease and the last children leave home to establish their own families of procreation. By stage VI, parents are endowed with new roles as grandparents. Parents and their children have established relationships that may allow them to interact more equally. By the final stage, VII, adult children must assume responsibility for their parents who are in failing health.

Life Cycle Stages. The interaction of biological and environmental factors within a developmental perspective forms the basis of the study of life cycle stages. Physical, cognitive, psychological, and sociological development in humans seem to take place in an orderly fashion where certain achievements or steps need to be taken before others in order for normal development to continue. The correlation between age and developmental achievements or stages is not strictly spelled out. Due to the stronger correlations of developmental stages to age ranges, life cycle stages have been assigned to age ranges by many researchers to suit the needs of their studies (see for example, Havighurst, 1952; Erikson, 1963; Piaget in Ginsburg and Opper, 1969; Levinson, et al., 1978). Each, however, posits the necessity of accomplishing certain tasks within one stage before moving successfully on

to the next.

Biological development stages have included adolescence or pubescence as the final stage in the physical development of humans. Though not as well studied as the earlier stages where biological development takes place at a much more rapid pace (Chinn, Drew and Logan, 1979:286), research shows that there is a systematic though not uniform development in adolescence which culminates in sexual maturity and attainment of final growth (Lefrancois, 1976:37-53).

In Piaget's theory of cognitive development, cognition develops in four distinct stages, the final period being formal operations, which begins about age twelve and is consolidated during adolescence (Ginsburg and Opper, 1969:181). The successive stages involve increasingly complex behavior (adaptation in Piaget's terms) as the result of the interaction of individuals whose physical and neurological complexity is steadily increasing and their constantly changing environment. The individuals reevaluate new information in terms of their internal established patterns (assimilation) and then rearrange their established patterns (accommodation) to form new behaviors (adaptation). At younger ages, assimilation and accommodation are relatively dominant, while adaptation is more evident in formal operations and continues as a life-long process (Sellin, 1979:91-93). During the formal operations stage the "adolescent's thought is flexible and effective. He can deal efficiently with the complex problems of reasoning. . . . The adolescent can imagine the many possibilities inherent in a situation. Unlike the . . . child [at an earlier stage] whose thought is tied to the concrete, the adolescent can transcend the immediate here and now" (Ginsburg and Opper, 1969:

181). Piaget (1972) has theorized that the period from fifteen to twenty years marks the beginning of professional specialization and consequently the construction of a life program corresponding to the aptitudes of the individual, but he had not researched this particular group to test this hypothesis.

Developmental psychology adds the notion of "critical periods"--certain periods when optimal growth and organization of a behavior system can be most easily affected (Fitzgerald, Strommer and McKinney, 1977:5)--to the notion of life cycle stages. If the certain developmental tasks which arise at or about a certain period in the individual's life are not successfully achieved during that period later development becomes more difficult (Havighurst, 1952).

Erikson has included the notion of critical periods in his "eight ages of man." The fifth stage closely ties in to the adolescent years. The major task of this stage, identity versus role confusion, finds the adolescent trying to cope with the psychological effects of rapid body changes and genital maturity. Similar to Piaget's ideas of assimilation, accommodation and adaptation, the adolescent strives for "a new sense of continuity and sameness . . . [to] form an ego identity . . . [which is] more than the sum of childhood identifications. It is the accrued experience of the ego's ability to integrate all identifications with . . . the aptitudes developed out of endowment, and with the opportunities offered in social roles" (Erikson, 1963:261). Should this integration into a firm identity not take place, there is danger of role confusion where adolescents doubt their ability to take adult roles, both sexually and occupationally. The negative resolution of the

identity versus role confusion conflict makes it difficult for adolescents (now young adults) to fuse their identities with others in stage six, intimacy versus isolation.

Vaillant (1977), as current director of a forty-year prospective study of the social and psychological development of white adult males through their adult life cycle, basically finds great support for Erikson's eight ages of man. Specifically, they found that there was a sequence to the stages of the life cycle and that a given stage of development could only be achieved when the previous one was mastered.

Developmental psychology has often focused on child development because of the critical developments which take place in rapid succession during the early years. Levinson et al., (1978) has taken the notion of developmental tasks and critical periods from child developmental psychology and applied it to adult development. Levinson, whose research is based on men's lives only, begins his division of the adult life course at age seventeen in the early adult transition which ends at age twenty-two. Within this period two tasks are to be accomplished:

> The first task is to start moving out of the pre-adult world: to question the nature of the world and one's place in it; to modify or terminate existing relationships with important persons, groups and institutions, to reappraise and modify the self that formed in it. . . . The second task is to make a preliminary step into the adult world: to explore its possibilities, to imagine oneself as a participant in it, to consolidate an initial adult identity, to make and test some preliminary choices for adult living (Levinson, et al., 1978:56-57).

This period is the first of five transitional phases in adult development, where the developmental tasks are to question and reappraise the life structure formed up to that point. The five transitional periods

are interspersed with four stable periods where the developmental tasks are to make firm choices, rebuild the life structure changed by the previous transitional phase, and to enhance one's life within the new life structure chosen. While unsuccessful accomplishment of the developmental tasks during early adult transition does not necessarily mean difficulty within the following stable period, from ages 22 to 28, it will present more difficulty in the age thirty transition where a developmental crisis can occur if the men find their life structure intolerable but seem unable to form a better one.

While it is difficult to separate psychological and social development during the life course, Elder (1975) has described some differences. Sociologists interested in life cycle stages have tended to focus on human development, socialization and adaptations as lifelong processes within an interage framework. Age differentiations are expressed in the sequence of roles and events, social transitions and turning points rather than the concern of developmental psychology which describes and explains age-related behavioral changes with a focus on the specification of linkages in antecedent-consequent relations. The sociological study of the life course introduces the concepts of social statuses--positions in a given social system, for example, mother and father; social role--the socially determined behavior of the person occupying the role; and role expectations--attitudes and beliefs about how the occupants of various statuses ought to play their roles or how they ought to behave. Role expectations involve certain obligations and privileges for the occupant of each status in relation to other statuses in the social system (adapted from Maloney and Ward, 1979:150).

Rosow (1974) has investigated adult development from the sociological life course perspective. While primarily analyzing the induction of elderly Americans into old age, he found that changes in the life cycle alter a person's social identity and relationships. Responsibilities and privileges invariably change over the life course as persons attain new statuses (for example, adult, parent, grandparent) and with these changes in statuses, the role expectations also change.

Family Careers, Life Cycle Stages and Mentally Retarded Persons. The previous two sections have dealt with the study of human development from the family career and life cycle stages perspectives for typical families and persons in our society. Mentally retarded children, however, do not develop fully through their life cycle stages, thereby restricting the development of their families' careers. Mentally retarded children and their families are therefore, exceptions to the perspectives discussed above. They represent a special area of study within these two perspectives, which may also include other families who have members with disabling conditions [such as sick children (Burton, 1975; Travis, 1976), mentally ill children (Park and Shapiro, 1976; Shepherd, Oppenheim and Mitchel, 1966) and children with physical handicaps (McMichael, 1971; Ayrault, 1971)]. Although no such study has been conducted, Farber (1975) has proposed a theoretical model by which the adaptation of these families could be studied.

Much of the research on families with mentally retarded children centers on the identification of the children's retardation and the families' reactions and adaptations to the diagnosis within the first

few years. Many of the studies are based on material gleaned from parents seen in outpatient, medical facilities, mostly white middle-class mothers of young, severely handicapped mentally retarded children (Robinson and Robinson, 1976:414). These studies' greatest failure is that they do not consider the long term effects of the child's disabilities on the children or their families. Several theories of parental reaction posit stages of grieving that parents go through in order to begin coping with their mentally retarded children (MacMillan, 1977: 236). These theories are static because parents of mentally retarded children go through many processes of adjusting their hopes and expectations. MacKeith (1974) has identified four periods when parents have to significantly readjust themselves during the growth of their mentally retarded children: 1) when the parents first learn about or suspect a handicap in their child; 2) when the child begins formal education; 3) when the child leaves school; and 4) when the parents become older. Each adjustment period demands that the family reappraise established life patterns and adjust accordingly to the new tasks in the subsequent periods.

Farber (1975) has developed the theory that families make

> . . . as minimal an adaptation as possible to solve problems involving family relationships. [He defines adaptation] . . . to be any sustained change in roles, norms or family interaction which family members make (individually or collectively) with the intention of effectively handling (by either solving or living with) the offensive situation. The minimal adaptation assumption implies a temporal progression of adaptations from the simple to the complex, from the least disruptive to the potentially fully disruptive. . . . Hypothetically, all things equal, families start out with the most minimal adaptations to their problems and proceed to

> successively more extensive and drastic ones only when the simpler adaptations are not effective (pp. 248-250).

Farber goes on to directly apply his theory of minimal adaptation to families with mentally retarded children.

> The continued presence of a severely mentally retarded child in the home represents a dynamic set of problems rather than a static problem. . . . Even in so called normal families, relationships are under continual pressure to change. This inherent instability derives from the fact that age-sex roles vary with movement in the family life cycle. As both children and parents age, role expectations are modified (p. 252).

Mentally retarded children do not, however, develop fast enough or far enough to allow the family career to continue as one would expect. Farber proposes that there is an arrest in the family career (p. 252). While normal children's statuses, roles and role expectations in the family change as children get older, mentally retarded children fail to meet the cognitive, psychological, and social expectations that their physical development engenders.

The study of the exceptions to the typical models of human and family development for mentally retarded persons and their families begins with the identification of the child. Obvious physical anomalies and/or extremely slow physical and/or social development for their age are often the precipitating factors which lead to the child's identification. This event, which occurs at birth or within the first three years of life for severely and moderately disabled children, has been characterized as "a highly traumatic, frequently tragic event" (Schwartz, 1970:74) for the parents. Taking into consideration the anticipation and excitement which precedes the birth of a child, and the frustrations

and adjustments to family life which occur after any child's birth, then the negative feelings families have when their children are identified as mentally retarded are understandable. The dream of the "perfect" child must be dealt with and some coping behaviors must be developed in order for parents and siblings to carry on everyday activities (Suelzle and Keenan, 1979:71).

It is precisely the identification of the child which sets in motion the process of adaptation by the family to the condition of the disabled member. The interaction of two factors--the maximum potential adaptive behavior of the disabled member and the economic, social and psychological resources of the family--determines to what extent adaptations will be made in order for the family to cope with its disabled member yet still remain a group, fulfilling various family tasks and socialization functions. The varieties of adaptation form a continuum along which family career and life cycle stages for mentally retarded persons can be studied.

The next major period of readjustment for families with mentally retarded children is the beginning of formal education for the child. Parents of all but the most severely handicapped children or those with extenuating home situations usually have no choice, but to keep their children at home and attempt to provide them with as normal a home life as possible. The primary referent group for the pre-school child is the family. So while the children may be behind developmentally for their age, parents can adjust their home lifestyles to meet the children's needs. The family provides most of the psychological, sociological and cognitive experiences for the preschool child. Upon entering

the educational system, however, the child's various abilities and disabilities are measured with the result that the child is usually placed in one of a variety of special education settings. Most likely children identified as mentally retarded before age three will be placed in special classrooms or special (segregated) schools.

The labeling of the child by the educational system (Mercer, 1973a; Gunn, 1978) communicates to parents or confirms parents' fears that their child is not like other children. Their child is not attending regular kindergarten or primary grade class, but is in classes with other handicapped children. At the time when other children are riding bicycles, learning to read and write, and participating in group recreation, their children are learning to coordinate their large muscles, beginning to recognize colors and sizes, and trying to control bodily functions.

The differences between mentally retarded children and others become more pronounced as the children grow older. As children grow up, persons in the community expect behaviors and acts to coincide with age and size. Behaviors which are considered 'cute' when children are small are inappropriate for older children (Suelzle and Keenan, 1979: 29; Birenbaum, 1971). Physically, mentally retarded children mature at about the same time or slightly later than other adolescents (Hall, 1974:186). While their sexual and physical maturation are nearly the same as other children, cognitive, psychological and social development are far behind normal adolescent development. The differences between physical size and the social, cognitive, and emotional skills of mentally retarded adolescents are painfully evident to adolescents and their

families.

Inhelder (1968:301-325), Piaget's closest associate, has described the cognitive development of the mentally retarded in contrast to normal children according to Piaget's theory of cognitive development. The transitions from one stage to another up to young adulthood become more and more rapid for the normal child, because during the stage of formal operations the adolescent is able to use the powers of abstraction to apply different possibilities to many situations. In the case of mentally retarded children there is a gradual decrease in the rate of development, which ends in stagnation at an earlier stage. Mental deficiency is defined by Inhelder as the incapacity to achieve the level of formal operations. While normal adolescents are able to reevaluate information in terms of their established patterns (assimilation) and then rearrange their established patterns (accommodation) to form new behaviors (adaptation), mentally retarded adolescents have greater difficulty adapting to new situations because assimilation and accommodation take precedence over adaptation. Mentally retarded children regress more frequently than do normal children to earlier long practiced modes of thought. When problems become more complex, they still try to solve it step-by-step and are unable to organize their assimilated patterns into new adaptations. They "simply repeat the same actions over and over, hoping somehow that the accumulation of the same actions will produce, sooner or later, the desired effect" (Inhelder, 1968: 325).

Mentally retarded adolescents face the same psychological challenges as the normal adolescent, that of adjusting to rapid body changes and genital maturity, yet their cognitive capacities are less

than those of normal adolescents. They, too, must resolve the identity versus role confusion task (Erikson, 1963), but may have neither the capacity nor the opportunity to successfully accomplish it. Studies show that mentally retarded adolescents are aware of their sexuality and strive for independence in much the same manner normal adolescents do (Morgenstern, 1973). Edmonson, McCombs and Wish (1979) found that I.Q. level was not a limitation on the sexual knowledge of mentally retarded persons, but that experience, instruction and interest were much more important factors. Therefore the lack of opportunity to attempt the challenges of adolescence may be more important than the lack of cognitive capacity.

The families with mentally retarded children have, by this time, well established patterns of adaptation. The education and support services provided through the school system have aided the families in coping with their children. Since the children progress through the special classes in much the same manner (but not, of course, at the same speed or content) that normal children do, a familiar routine has been established that approximates that of other children. Social roles in families are being strained however, because mentally retarded children have not taken on age-appropriate responsibility and yet still demand the attention that much younger children would. Mentally retarded adolescents with siblings will have moved to the status of youngest child because the level of family tasks performed and responsibilities taken is much less than that of younger siblings (Farber, 1968:158). An incongruency exists in adolescence for mentally retarded persons. Their roles in the family have stagnated at a childhood level yet the

challenges of adolescence, which with ample opportunity can be accomplished, demand increased independence in order to bring them to a positive resolution.

The schools with their special education classes and supportive services have provided the opportunities for adolescent development to begin. The end of formal education and the subsequent dearth of comprehensive coordinated service system for mentally retarded adults blocks the resolution of adolescent development and arrests family career development completely, causing the family, once again, to begin to significantly readjust their roles to the changing needs of their disabled member.

Mentally retarded young adults are unable to begin the adult life course as described by Levinson, et al., (1978) because almost any measure of independence from the family of orientation is not possible due to the lack of adequate services to support the transition (Rowitz, 1975:10). Instead the parents reassume the role of primary referent group for their child. Parents, who might otherwise be moving on to a stage in the family career where they would be reformulating their relationship with their spouse, are instead continuing responsibility for their adult child. Only with increased assistance during this transition to adulthood can mentally retarded young adults have the opportunity to continue the life cycle into a form of independent adult living, and the parents, to continue the course of their family career.

The continuation of the life cycle stages and family careers, however, only approximates those of typical families because the parents must continue the supervision of their adult children to ensure that

proper services are and will be provided when the parents die. It is the fear of their own deaths before that of their mentally retarded children which often motivates parents to take action with other parents of mentally retarded adult children to ensure an adequate provision of service. Also, while older parents can assume that their children will take care of them as their health fails, older parents of mentally retarded children cannot expect that from their children. They can only plan to transfer their responsibilities for their disabled child to other family members or institutions.

D. Planning Services for Mentally Retarded Persons

The planning and organizing of services are as important as the prevention and treatment services. Difficulties experienced by parents, their mentally retarded children, and concerned practitioners often stem from lack of services to complement existing services, duplication that drains service resources at a time when fiscal restraint is in vogue, and a lack of jurisdiction for service delivery. The organization and delivery of services should allow for an orderly progression through family career and life cycle stages and each of the service elements should be consistent and integrated (Sellin, 1979: 212, 238). With careful planning, developed from a research base, judicious use of resources can provide the most equitable service system possible. In this section, planning services for mentally retarded persons will be explored from two perspectives: 1) What is planning and how reasonable is it to plan? and 2) Should parents be included in the planning process?

Why Plan? "Planning is determining in advance the objectives to be accomplished and the means by which these objectives are to be attained. It is deciding what to do, how to do it, and who is to do it" (Robbins, 1976:15-16). Planning is an attempt to anticipate future changes by using the past and the present. In the world of business, it has been shown that organizations engaging in formal long-range (at least three years) planning outperform organizations that plan on an informal basis (Herold, 1972; Thune and House, 1970). Planning can give direction, improve continuity of services, and reduce overlapping of service functions.

Planning, its process and product, is dependent upon the orientations of the persons involved. Hyman (1976:69-71) identifies two types of planning orientation. Means-oriented planning stresses the steps of planning which will allow for the most efficient alternative to attain the goals. The focus is not on the goals but how to achieve them in the most efficient way possible. Means-oriented planning emphasizes how to maintain a balance in allocating existing resources for well-established goals rather than trying to foster a new set of goals. Goal-oriented planning is essentially designed to change the system or substitute it with another one. Its focus is on reform and innovation to reach a new set of goals which may be radically different from existing well-established goals.

The current fiscal cutbacks in the 1980's have precipitated a more means-oriented approach to planning. As mandates for across-the-board cutbacks without loss of services to clients begin to hit government budgets at the federal, state and local levels, planners react by

figuring how to maintain the same goals by reallocating resources. In contrast during the early 1960's the Community Mental Health Centers Act (P.L. 88-164) was a product of goal-oriented planning, where the mental health service goal was to switch from an institutionally-based system to a community-based system. The excellent condition of the United States economy, the personal interest of President Kennedy in mental health and mental retardation programs, the advent of psychiatric drugs, and the societal awareness of the harmful consequences of institutionalization precipitated a receptive climate where new goals could be introduced and implemented (Mechanic, 1980:81-82).

Therefore, planning exists within "a continually changing system of values which identifies social preferences at any particular point in time" (Kurtz, 1977:135). While planners try to incorporate both technological changes and societal values into the planning process, they face a society that does not change easily. We are "crisis-oriented and reaction-motivated" (Begab, 1975:4). Planners face a scenario in which societal interest in particular social problems waxes and wanes with successive "crises" (Albrecht, 1976:258-260).

Planning in the early 1980's must take into consideration the current "tax-cutting" mood of the country. Due to the constraints of such resources as time and money, only a limited number of issues can receive top priority. At the present time curbing government spending, increasing defense spending, and domestic energy development are examples of high national priorities, leaving human services, in general, trying to contend with constant or slightly rising expectations and constrained or reduced budgets.

It must be realized, however, that planning is no panacea to rectify budget cuts or service reduction. Judicious planning can allocate limited resources so as to serve persons in the most equitable fashion possible. Planning cannot guarantee success in the goals to be achieved. If planning is not done, goals are not identified, priorities are not established and the organization is unable to anticipate future changes. Planning enables organizations and persons to logically anticipate future situations.

Who Plans? The plan of an organization can be the product of one person acting in a staff function to an agency director or it can be the product of an intensive process which seeks the input of all persons who can be affected by the plan. The advantages of the former are that it is probably inexpensive to do, produces a plan within a short amount of time, and can be as highly confidential as it needs to be. The advantages of the latter are that in the process of developing the plan, all participants are fully aware of the compromises and negotiations that take place to produce the plan and all have a vested interest in its stated objectives and goals, making its implementation more likely. In planning for publicly-funded services the latter alternative is preferable. Unfortunately, both methods of planning can be just as likely to sit on the shelf gathering dust. Implementation of a plan depends upon its pertinence to existing organizational and societal conditions and the commitment of vested interests in accomplishing its goals and objectives.

Planning for services to mentally retarded persons has changed dramatically over the past twenty-five years. Community services in the

1950's were being developed by private interests, usually parent associations. They were set up independently in hundreds of different localities around the United States without any concerted hierarchical planning by state or federal government (Katz, 1961). As the parent associations successfully lobbied for the provision of community services through public institutions, such as local or state educational agencies, planning of these services became formalized, with administration being done by professionals. State and federal agencies developed planning departments to plan for future services. Professionals, with more in-depth knowledge became the "experts" and parents were excluded from the planning process. With the passage of P.L. 94-142, The Education for All Handicapped Children Act, parents were formally made partners in the planning process of their children's curricula. This role of partner has been encouraged by a few (such as Biklen, 1974; and Hobbs, 1975: 229) so that parents would be involved in the planning process at all levels, for all services, for the entire life cycles of the children.

Parents should be involved in the planning process because of their life-long responsibility for their mentally retarded children (Robinson and Robinson, 1976:431; Rowitz, 1974:411; Keenan and Suelzle, 1980). They and their children stand to gain the most from participation in planning. McKnight warns against the problems caused in a service system overburdened by professionals with their own vested interests. "In an overserviced society, the needs themselves are defined by the professionals, not by the people in need; experts supply not only the therapies and answers, but also the questions" (DeZutter, 1980:43). Involving parents ensures that their needs will be heard.

But even if all the needs of parents of mentally retarded children were known, there would be difficulty in making priorities and translating needs into actual community services. Needs of mentally retarded children vary from child to child and the needs of each child vary from time to time. The capacity to meet these needs also varies from family to family and the capacity of each family varies from time to time. Therefore services must vary to meet these different needs and capacities (Dempsey, 1975:190-191). Special interest groups sometimes reflect needs of sponsors rather than clients and limited funds and entrenched funding cycles prevent new services or expansion of old services (Katz, 1968:79).

With the advent of comprehensive coordinated service delivery in the last ten years, the goals of planning have been to coordinate existing services, to identify gaps in the delivery system, and to begin to fill those gaps and upgrade existing services. As parents assume a more integral role in the planning process for all services, then comprehensive attention will be paid to the whole environment that influences the education and development of mentally retarded persons. This philosophy should pervade the service system. Families should be considered the primary resource and source of help for handicapped children. They have continued responsibility for the children and are the most significant change agents for behaviors and attitudes. Finally, "parents have the need and the right to play a part in the decisions made concerning their children" (Falck, 1976:231).

E. Normalization

The concepts of normalization and deinstitutionalization form the basis for the current community-based service system for mentally retarded persons. In this section the concepts will be defined and discussed in terms of the relationship between the philosophies and their application and what effect these applications have had and will have on mentally retarded persons and their families.

Definition. The philosophy of normalization simply stated says that the lives of mentally retarded persons should be as normal as possible. Nirje (1976:364-367) has outlined a description of the application of the normalization principle, summarized below.

> 1. Normalization means a normal rhythm for mentally retarded persons (for example, getting out of bed and getting dressed even if profoundly retarded).
>
> 2. Normalization implies a normal routine of life. Most people live in one place, work or attend school somewhere else and have leisure-time activities in a variety of places. With wider experiences and proper social training, mentally retarded persons can use the normal leisure-time facilities of the society on their own, and also learn to cope with unprepared, unstructured situations without panicking.
>
> 3. Normalization means to experience the normal rhythm of the year, with holidays, vacation, and family days of personal significance.
>
> 4. Normalization means an opportunity to undergo normal developmental experiences of the life cycle. Children should have warmth of atmosphere, rich sensory stimulation and surroundings, and settings of proper proportions. Youngsters and adolescents of school age who are mentally retarded never live in a confined setting together with mentally retarded adults. Their socializations and impressions of life should be gained as much as possible through contacts in normal society. For mentally retarded persons growing

from adolescence into adulthood is often a longer, more painful, and more uncertain process than for others. Their images of themselves often become confused. They are not always accepted, treated, and respected as adults. Attitudes of others towards them are important. Thus, like everyone else, mentally retarded persons should experience the coming of adulthood through marked changes in the settings and circumstances of their lives. Just as it is normal for children to live with their parents, so it is normal for adults to move away from home and start lives on their own as independently as possible. Training programs for mentally retarded young adults should assist them to become as competent and independent in their personal daily routine as possible, and to develop social skills which will enable them to take part in the regular community life as much as they can. The period of old age, when work is no longer possible or feasible, consists for most people of contacts with the familiar settings and acquaintances that have given life so much of its content and meaning.

5. The normalization process means that choices, wishes and desires of mentally retarded persons have to be taken into consideration as nearly as possible and respected.

6. Normalization means living in a bisexual world.

7. A prerequisite to letting mentally retarded persons obtain an existence as close to normal as possible is to apply normal economic standards. They should be given basic monetary privileges available to others.

8. An important part of normalization implies that standards of physical facilities should be the same as those regularly applied in society. Therefore, sizes of facilities should conform to what is normal and human in society and plans for the location of facilities should never include isolated settings.

Deinstitutionalization and Mainstreaming. The application of the normalization philosophy has different nomenclature in different societal institutions. In residential services to mentally retarded persons the word "deinstitutionalization" was coined to describe the change in orientation from institution-based services to community-based services. In educational services to mentally retarded children the word

"mainstreaming" is used to indicate the provision of educational services in the least restrictive setting.

Unfortunately, as Begab (1975:26) points out, "normalization is more a philosophy of human rights than a prescription for treatment." The community-based services have helped families with mentally retarded children to approximate normality (Birenbaum, 1971:56), but this may be only a temporary phenomenon due to the extensive support provided by the educational system. The lack of community support for services to mentally retarded adults shows up in institutional admissions data. Scheerenberger (1976:85-86, 170, 171) found that while some data seem to support deinstitutionalization (for example the significant decrease since 1964 in the number of residents less than 21 years and the reduction of mild and moderates as a percentage of all institutionalized); others indicate that many problems remain. For example, there has been a significant increase in the number of residents over 21 years since 1964 and many of these adults are less seriously affected and theoretically should not need institutionalization. He concludes that community programs are not being developed as rapidly as desirable, and that the data also dispell the commonly-held belief that new admissions are limited to very young and severely retarded children.

What seems to be the trend is that institutionalization is being postponed from early childhood and adolescence until young adulthood. This has been made possible by the provision of educational services by publicly-funded education until 21 years under Public Law 94-142. There are widely divergent opinions as to the success of P.L. 94-142 and "mainstreaming." While the controversy rages over its effect for the educably

or mildly mentally retarded children (Childs, 1979a; Warren, 1979; Blatt, 1979; Childs, 1979b), the trainably (or moderately) and severely and profoundly handicapped children seem to have benefitted greatly, though MacMillan (1977:448-452) identifies some potential problem areas. But while support is provided for families during their children's early years, mentally retarded children are ill-prepared to become mentally retarded adults (Burton, 1976:191).

Studies of mentally retarded adults in the community seem to bear this out. Edgerton's seminal work found that many deinstitutionalized mildly handicapped adults had a difficult time adjusting to community living because of the stigma attached to their disability and that their efforts and capacities to deal with this stigma were limited (1967:208). Edgerton and Bercovici's follow-up (1976) of this same group more than ten years later found that many had improved their life circumstances but in a number of cases, original predictions of the direction and nature of their community adjustment proved to be inaccurate. Individual social adjustments fluctuated greatly over time making prognostication difficult.

Birenbaum and Seiffer (1976) and Birenbaum and Re's (1979) longitudinal studies of deinstitutionalized mentally retarded adults found them to be steadily involved in sheltered workshops and have some peer relationships but less involved in community leisure activities and personal decision-making than was expected. They conclude that there is no sequence of moving from dependency to self-reliance in community residence. Community-based residence and easy access to mass transportation cannot by themselves provide greater participation in leisure time activities in the community.

Mainstreaming and deinstitutionalization have not provided the means for mentally retarded adults to participate fully within the community and it is not likely that they will be able to in the near future. High unemployment rates make it more difficult to find jobs and to become more independent and self-sufficient (Wing and Olson, 1979:178). The idea of community-based services must be tempered to realistically reflect social and economic constraints in the society. Just because a service is being provided in the community does not alone make it qualitatively better than services provided in a day or residential unit of an institution. Very often the limiting factor is not the location of the service but the severity of the persons' disabilities (Wing and Olson, 1979:176) and the quality of the staff (Hobbs, 1975: 201-202). Instead of focussing on location of services, more can be gained by linking services into a network which can support mentally retarded adults in the same manner as the educational and auxiliary services support mentally retarded children and their families.

Future Possibilities. Normalization as a philosophy of treatment and lifestyle has some strong backing from two interesting examples of work opportunities for mentally retarded adults. Marc Gold has developed gainful employment opportunities for severely and profoundly mentally retarded persons through the development of appropriate technology to allow these persons to perform complex tasks such as bicycle brake assembly. He believes that low expectancy of society, not incapability of the handicapped is the single most critical deterent to their gainful employment. Low-level jobs for the handicapped create low self-esteem

which is influenced by expectations and feedback from others. He hypothesizes (1975:257, 260) that a significant upgrading of the kinds of jobs performed by mentally retarded persons would result in greater self-esteem and better job performance. Since gainful employment and the nature of work provide persons with their most reliable means of obtaining basic privileges and acceptance, the more competent mentally retarded persons are, the more their other shortcomings will be tolerated in others.

A similar concept which builds on Gold's developments is Lance and John Du Rand's affirmative industry (1978). They believe that full participation in society by the handicapped is hampered by non-productive, non-contributing and socially dependent occupations. They developed the affirmative industry to provide employment opportunities for those persons whose handicapping conditions prevent them from full employment in the open-job market. They have been able to employ 70% of those individuals now generally restricted to pre-vocational work activities programs. The key to full participation by mentally retarded adults rests with the creation of appropriate programs and technologies (such as Gold's) to train the handicapped for productive occupations and the proliferation of appropriate employers (such as the affirmative industry).

In the near future the application of the normalization philosophy to the residential and vocational services for mentally retarded young adults and adults will succeed or fail depending upon the availability of integrated support services. The support services have a double-edged task. On the one hand they should provide enough guidance and support to allow the mentally retarded adults to function as fully as

possible in the community. On the other hand, the services cannot be so overprotective as to isolate the adults within the community. The accomplishment of this task requires the recognition of what Perske (1972) calls the dignity of risk. Risk is a "normal" aspect of life and socialization. Not allowing mentally retarded adults the risk of both success and failure by overprotecting them can be as dehumanizing as providing no follow-along or support services to those functioning semi-independently in the community.

Advocacy

Advocacy for mentally retarded persons is a growing social movement much like the growing child advocacy and consumer advocacy movements (Paul, 1977), that has the well-supported intentions of providing more effective integrated services. But due to the growth of the service industry that has developed around the needs of the developmentally disabled, advocacy also tries to defend mentally retarded persons against services, no matter how well intended, that favor the interest of the service system at the expense of mentally retarded persons. In this section, the theory behind advocacy will be explored, along with the role that families have in the advocacy movement.

Advocacy and social change. Etzioni has studied the rise and fall of social movements, like advocacy, and has found that the greater the ability of the individuals and groups to take part in planning and guiding social change, the more freedom they have from their history. (That is, the easier it is for them to change imbedded cultural and

personal values.) Where individuals and groups do not have this ability or they do not exercise their ability to participate, the more they are bound by policies and conditions they had no part in developing (Etzioni and Richardson, 1975).

In order to guide social change, social action must be involved. Social action is "the process and the strategy by which you find, motivate, mobilize, and organize resources (individuals, groups, as well as materials) in order to accomplish a predetermined end" (Sellin, 1979: 220). In order to carry out the process, three components are necessary change agents (who supply the initial effort and provide the central organization), legitimizers (who provide the support, guidance, authority or justification to act), and the active participants (who provide the day-to-day effort and some of the resources) (Sellin, 1979:221).

Parents of mentally retarded children have organized themselves in the past to supply services and create a social movement (Katz, 1961) which has great potential for including more of the handicapped in the mainstream of society than ever before. However, the growth of the professional bureaucracy (DeZutter, 1980) has made it necessary for an advocacy movement to develop which can act as a balance to the professional associations (Felicetti, 1975). In order to legitimize their function, the change agents of the advocacy movement need to gain community support and acceptance in the same manner that parents' groups did in the 1950's (Wolfensberger, 1973). Instead of allowing the institutions to provide advocates for their mentally retarded children, parents must be the ones empowered to act as advocates for their children (Hobbs, 1975:224).

A system of advocacy should include the following capabilities (adapted from Pelosi, 1977:34):

> 1. It should be able to monitor and assess the interaction between mentally retarded persons and their environment to identify advocacy needs and the network of services to evaluate the effectiveness of service delivery.
>
> 2. It should be able to act on behalf of individuals or groups of developmentally disabled persons to resolve advocacy needs situations.
>
> 3. It should be able to involve community and neighborhood consumers, parents, and other concerned citizens in directing, maintaining, and owning the advocacy system.

Parents and advocacy. Much allusion is made in the literature to the importance of parents' roles in the planning and provision of services to their mentally retarded children (for example, see Bardwell, 1976; Katz, 1961; Matheny and Vernick, 1969; Paluszny, 1979:137; Paul, Turnbull and Cruickshank, 1977:20; Rowitz, 1974; Schopler, 1976; and Sternlicht and Deutch, 1972:36). There have been few programs cited that do involve parents in the planning and provision of services, though a more thorough search of the literature needs to be done. Even fewer programs involve parents to the degree that their role demands. Karnes, Zehrbach and Teska (1977) believe that parent involvement is limited due to two factors: the attitudes of professional personnel and their lack of skills in working with parents.

For parents their role as advocates for their mentally retarded children is a continuing one (see Suelzle and Keenan, 1979:97-134). When the children are young, parents keep detailed records to ensure proper diagnosis, assessment, and placement in educational services. During their school years, parents monitor and select appropriate

developmental programming through their involvement in their child's individual educational plan (IEP). As the children near the end of their schooling and as parents become older they face their ultimate concern, "What will happen to my child when I'm not here?" (Sellin, 1979:370). At this time parents need the services of a citizen advocacy program to ensure their adult children's relationships with capable volunteer advocates who can defend their rights and interests while providing practical and emotional reinforcement (Copeland, Addison, and McCann, 1974:8).

CHAPTER II. HYPOTHESES AND METHODOLOGY

The first section presents a detailed discussion of the hypotheses and a summarization of the predicted associations made between the independent and the dependent variables. The data base to be used for investigating parents' choices for future residential and vocational opportunities for their mentally retarded children is described in the second part of this chapter. In the third part of this chapter a detailed explanation of the variables and methods used in the analysis is provided.

A. Hypotheses

The purpose of this study is to investigate factors which influence parents' planning for future services for their mentally retarded children. Since parents have primary responsibility for these children throughout their lifetimes, planning services for mentally retarded adults is dependent upon understanding parents' hopes and attitudes for the future. The hypotheses which follow are summarized in Table I and their specific predicted relationships are discussed below.

Parents' Planning. As the dependent variables under consideration, parents' planning for future services can be divided into two categories: long-range planning and current attitudes as precursors of long-range planning. Long-range planning considers parents' choices for residential and occupational opportunities, when their children make the transition from adolescence to adulthood. It can be measured

Table I

Summary of Hypotheses About the Direction of the Predicted Associations Between Residential and Vocational Planning (Dependent Variables) and Family Demographics, Family Career, Community Involvement and Advocacy, Child's Characteristics, and Extended Family

	Project Residential Future	Project Institutionalization at Age 21	Project Sheltered Work at Age 21	Pro- Mainstreaming
Family Demographics				
Family Income	+	+	+	-
Race, White	+	+	+	-
Mother's Education	+	+	+	None
Grandparent(s) Living	-	-	+	None
Currently Married	-	-	+	None
Child at Home	-	-	-	+
Family Career				
Mother's Age	+	+	+	-
Mother's Stress	+	+	+	-
Parents' Stress	+	+	+	-
Parents' Time Constrained	+	+	+	-
Community Involvement and Advocacy				
Community Acceptance	-	-	-	+
Friends' Advice	+	+	+	-
Feeling Excluded	-	-	-	+
Political Participation	+	+	+	-
Child's Characteristics				
Low Cognitive Skills	+	+	+	-
Low Social Skills	+	+	+	-
Child's Sex, Male	+	+	-	+
Child's Age	+	+	+	-
Extended Family				
Grandparents Accept Child	-	-	-	+
Grandparents Support Parents	+	+	+	-

by examining parents' intentions to secure future residential care for their children and by identifying parents' projected occupational and residential settings for their children at age twenty-one. Parents' current attitudes towards principles guiding their children's present programs reflect latent long-range planning. For example, parents' favorability towards mainstreaming in their children's current school programs would be congruent with parents' long-range plans for community-based residential and occupational settings. Conversely, parents' opposition to mainstreaming in their children's school program would be congruent with long-range plans for institution-like residential and occupational settings. Parents' attitudes towards programmatic principles are the bases for future decision making about appropriate vocational and residential settings.

The Independent Variables. Farber's theory of minimal adaptation (1975) provides a framework for examining variations in parents' planning. He derived this theory from rethinking the results of his original study which proposed that different family types (for example, child-oriented and parent-oriented) were the theoretical bases for understanding families' adaptations to their mentally retarded children. The minimal adaptation theory is seen as a further specification of the family types theory. While Farber's theory of minimal adaptation suggests a longitudinal study (in order to assess the process of minimal adaptation), the present study uses cross-sectional data and controls for age. This presents some difficulty for data analyses because what are deemed longitudinal effects could be the result of historical effects.

He hypothesizes that families will make as minimal an adaptation as possible in order to solve problems involving family relationships. In the case of families with mentally retarded members, he hypothesizes that adaptations will vary according to the amount of time and energy demanded by the mentally retarded children, the extent of family resources, and prior loyalties and commitments. In the same manner, I hypothesize that parents will plan for future services according to the amounts and kinds of resources families are able to bring to bear on problems caused by having mentally retarded members. Variations within parents' planning may be explained through studying families as nuclear units within a vast community network, as suggested by Rowitz (1974). In this study, independent variables focus on families' personal and primary resources as a starting point for examining families within the whole community service system.

Family Demographics. Family resources can be measured by looking at standard family demographics, such as socioeconomic status, family composition and availability of extended family. Farber (1968: 154, 197; 1975:259) predicts that the higher the socioeconomic status of families the greater will be the discrepancies between families' social and economic expectations for children and the mentally retarded children's abilities to meet those expectations. The greater emotional impact for higher socioeconomic families means they will be more likely to extrude mentally retarded children. Therefore, I predict that families with higher incomes, white families, and more highly educated parents will be more likely to plan for more restricted

residential and vocational settings. Conversely, I predict families with higher incomes and white families to be less supportive of mainstreaming. For the relationship between parents' education and mainstreaming, I make no predictions because I expect a value conflict between goals desired for the children and families' social and occupational obligations.

I assume that families' abilities to cope with their mentally retarded children are enhanced when parents are currently married and at least one grandparent is living. The more adults there are involved in the families, the better able families are to cope. Therefore, I predict that families with at least one grandparent living and where the parents are currently married will be less likely to have planned future residential placement for their children or to plan for a more restricted residential setting at age twenty-one. Conversely, in the same families, parents will be more likely to plan for more sheltered work environments at age twenty-one because they will be able to support their children as dependent adults. For the relationships between grandparents living or marital status and parents' beliefs about mainstreaming, I make no predictions because I believe that neither marital status nor grandparents' availability would affect parents' attitudes towards principles guiding their children's programs.

Parents' planning for future services will be greatly affected if their children are already institutionalized. Since the recent literature has not focussed on mentally retarded children who remain at home (although substantial work was done during the 1950's in England, see Tizard and Grad, 1961), predictions need to be drawn from

the literature on institutionalization and deinstitutionalization and applied to the case of children at home (such as Fotheringham, Skelton, and Hoddinott, 1971).

The Carvers (1972:119-130) discuss the readjustment to more "normal" roles in families where mentally retarded children have been institutionalized. The readjustment process acts to normalize relationships within the family which had previously been strained. As Mercer (1966) and Birenbaum and Seiffer (1976) point out, these families may resist the deinstitutionalization of their children. Therefore, I predict that families with mentally retarded children at home will be less likely to plan for more restricted residential and vocational settings. Conversely, I predict families with mentally retarded children at home will be more supportive of mainstreaming.

Family Career. Family resources can also be measured by the concept of the family career. Roles of family members tend to be qualitatively different at each stage of the family career. For families with mentally retarded children the inability of mentally retarded members to assume different roles in progressive stages can bring families' careers to a halt (Birenbaum, 1971). I assume that this arrest in family development causes strains within the family, especially with mothers' personal lives and in husband-wife relations.

Baroff (1974:23), Ayrault (1971:165), Adams (1972:115) and Birenbaum and Seiffer (1976:75) discuss the process whereby aging parents realize their own mortality and consequently become quite anxious about their children's futures. Therefore, I predict that

older parents will be more likely to plan for more restricted residential and vocational settings. Conversely, older parents will be less likely to support mainstreaming.

Even with "normal" families (Aldous, 1978:275) and families whose children had physical disabilities only (Ayrault, 1971:65), stresses in parent-child relations feed back into husband-wife relations. For families with mentally retarded children stress in coping with the children can lead to their extrusion from the family (Tizard and Grad, 1961:88; Mercer, 1966; Farber, 1968:194; Birenbaum, 1971:52, 62; Rutter, 1971:207). I predict that parents of mentally retarded children experiencing more stress individually and in their relationships with their spouses will be more likely to plan for more restricted residential and vocational settings.

Nirje (1976:369) and Rutter (1971:207) believe that the more normalized families' situations are, the easier it is for parents to take advantage of community services to benefit their children. Mainstreaming has been conceptualized in this paper as the application of the normalization principle in educational institutions (see pp. 32-35). Therefore, I predict that parents experiencing more stress individually and in their relationships with their spouses (that is, less normalized situations due to having mentally retarded children) will be less likely to favor mainstreaming.

Community Involvement and Advocacy. The study of decision-making of families with mentally retarded children has to be seen as part of a community network (Rowitz, 1974:411). Personal and community

supports, informal and formal groups, are resources that families use to cope and to arrive at solutions about how to maintain lives (Mechanic, 1980:108, 110).

I predict that parents who perceive their neighbors as accepting their children in a variety of social situations throughout their children's life cycles will be less likely to plan more restricted residential and vocational opportunities. Conversely, they will be more likely to favor mainstreaming.

Parents who consult friends and family frequently for advice about their mentally retarded children are predicted to be less likely to favor mainstreaming and more likely to plan more restricted residential and vocational opportunities. I am assuming that the context of advice from family and friends would be more traditional than that of school personnel.

Parents active in advocacy groups or parents' groups and governing boards have tended to be middle-class, white, and to be parents of children who are more severely handicapped (Katz, 1961). Therefore, I predict that parents who are more politically active will be influenced by the vested interests of that white, middle-class group. That is, I predict parents who are more politically active will make plans for more restricted residential and vocational opportunities. Conversely, more politically active parents will be less likely to favor mainstreaming.

Parents who feel excluded from parent groups may be at the opposite end of the continuum from those who are politically active (that is, they may be parents of less severely handicapped children, of lower socioeconomic status, and non-white). I predict that parents who feel

excluded from parents' groups will be less likely to plan for restricted residential and vocational opportunities and more likely to be in favor of mainstreaming.

Child's Characteristics. The lack of skills necessary to cope with modern society exacerbates people's problems in assuming ordinary social roles (Mechanic, 1980:113). For families with mentally retarded children, the nature of the children's handicaps is the most important factor causing problems within the family (Wing and Gold, 1979:106). The more severe the disability, the more likely parents are to extrude the child from the family (Carver and Carver, 1972:53; Farber, 1968: 162; Mercer, 1966).

In families where the children's cognitive skills and social skills are more impaired, parents will be more likely to plan for more restricted residential and occupational opportunities. Conversely, in these same families, parents will be less likely to favor mainstreaming.

Farber (1968:157) found that mentally retarded males seem to create greater stresses for their families than do females. Therefore, I predict that parents of mentally retarded males will be more likely to have secured a future residential setting and to plan more restricted residential opportunities. Bayley (1973:154-157) found in a community study of severely subnormal adults that slightly more males than females were employed in the open market. Therefore, I predict that parents of mentally retarded males will be more likely to plan less restricted occupational opportunities and to favor mainstreaming.

As mentally retarded children grow older, the differences

increase between them and other children of the same chronological age. Parents realize that their mentally retarded children will not catch up, and parents adjust their expectations (Birenbaum, 1971:16). I predict the older the mentally retarded child, the more likely parents are to plan more restricted residential and vocational opportunities, and the less likely they will be to support mainstreaming.

Extended Family. More meaningful measures of extended family resources than merely grandparent availability (that is, whether at least one grandparent is alive or not) are measures of the type of support grandparents give. In this study the two conceptually distinct measures of grandparents' support are provided. Grandparents' acceptance of their mentally retarded grandchildren assesses grandparents' acceptance of the children as if they were "normal" grandchildren. Grandparents' support of parents measures grandparents' support of the parents' style of childrearing, realizing the limitations of the children.

I predict that in families where grandparents accept their mentally retarded grandchildren (that is, accept the children as if they were "normal"), parents will be less likely to plan for more restricted residential and occupational opportunities. Conversely, in these families, parents will be more likely to favor mainstreaming.

For families where grandparents support the parents (accepting the children's limitations), parents will be more likely to plan more restricted residential and vocational opportunities. Conversely, in these families, parents will be less favorable towards mainstreaming.

B. Research Methodology

In order to conduct original basic research on the decision-making process of parents whose children have mental retardation, a project was undertaken for the period beginning July 1977 with funding for two years from the Extramural Research and Development Grants Program of the Illinois Department of Mental Health and Developmental Disabilities.

The study was conducted in Lake County, Illinois. The county is in close proximity to Northwestern University, which minimized travel time and expense. Lake County offers a wide range of services to mentally retarded people. There is a major state-operated residential center for severely and profoundly retarded persons. There are other smaller residential programs operated by private non-profit groups. The county is known for its comprehensive programs of special education offered through the public school districts. There are several sheltered workshop facilities for mentally retarded persons. Within the area alternative residential programs for mentally retarded persons are beginning to be developed (for example, community living facilities, foster home networks, groups homes).

The area of Lake County was selected for the research population because: (1) it is geographically compact yet includes urban, suburban and rural populations; (2) it offers a wide variety of services for mentally retarded persons; (3) providers and consumers of services have a history of cooperation with past efforts to secure related information; and (4) the county contains people of a wide range

of socioeconomic, racial and ethnic backgrounds.

Sampling was not necessary because the population and delivery system was small enough to include all families and all service providers.

Depth Interviews. An earlier study, conducted during the Summer 1976 under a grant from the Russell Sage Foundation to study early childhood socialization practices, provided data which informed the present study. One aspect of that research project involved conducting focused group interviews with parents of children regularly receiving child care services outside the home. The interviews involved discussions of several aspects of parental child care decision making: the initial decision to have children cared for outside of own homes, the decision to have children enrolled in present placement, satisfaction and dissatisfactions with the alternative selected, types of social environment desired, and their participation in center activities.

Twelve group interviews were conducted, ten with parents whose children were in centers serving normal children, and two with parents whose children were in centers for mentally retarded children (Park School, a program for trainable mentally handicapped children in Evanston, and Waukegan Developmental Center, a State-operated residential facility for the training and care of severely and profoundly mentally retarded persons).

Because the number of interviews was small, the results of this study were regarded as exploratory. However, a dramatic difference in the decision making processes of the two groups of parents was noticed

as they sought out appropriate services for their children. Because the general public's experience interacting with mentally retarded persons is very limited, the parents of these children were not able to avail themselves of the usual networks of information (i.e., from parents, friends, neighbors) regarding children's services, networks that are available to parents of "normal" children. As a result of this information vacuum, the advice of the family's primary physician took on an added weight. Often this information complicated the parents' decision making process due to its highly technical nature and the physicians' ignorance of the child's future potential and the current delivery system of developmental disability services. These exploratory interviews indicated that these parents were confused, isolated and perceived themselves as inadequate to make an appropriate choice of services for their mentally retarded children. If the situation is as serious as this exploratory research indicated, then it seemed necessary to study the issue on a larger scale to define the situation more clearly and to indicate some feasible course of action that would assist parents attempting to make an appropriate choice of services for their mentally retarded children.

It was decided to conduct additional depth interviews with individual families to explore more fully the decision making process when seeking services for a mentally retarded child. It was felt the depth interviews would provide detailed information about the resources and service gaps in Lake County itself thus adding important information to a review of the literature for informing construction of the quantitative mail survey questionnaire. An opportunity to contact parents

for this purpose was provided through the Lake County Developmental Disabilities Sub-Area (D.D.S.A.) Planning Group.

In September 1976 members of the Lake County D.D.S.A. Planning Group developed and sent out a four-page questionnaire to approximately 500 families identified as having one or more mentally retarded children. The survey listed community services utilized by mentally retarded persons and their families--educational, residential, recreational, transportation, supportive, and health--and asked parents to identify services being used presently as well as services they expected to need for their children within the next five years. At the end of the questionnaire an item was included which asked, "Are you willing to answer additional questions in the future regarding the needs of mentally retarded persons?" Space was provided for positive respondents to include their name, address, and telephone number. Individuals responsible for the development of this survey provided this project with both letters of support, and the names, addresses and telephone numbers of parents willing to be interviewed, along with the ages of their mentally retarded children, and the nature of the disability. Ten families to be interviewed were selected so as to provide variation in the nature of mental retardation and the age of the children for whom services were sought. Parents of mentally retarded, autistic, and epileptic children ranging in age from fourteen months to twenty years old were interviewed, including both black and white families.

At this point the interviews did not seem to be providing further new major insights, but we realized that all our interviews had been conducted with intact two-parent families. Since we felt the

experience of single parents might be significantly different insofar as they had less economic and interpersonal resources than two-parent families, we utilized our own networks to locate two single parents, both mothers, who agreed to be interviewed. One resided in Lake County, the other in Evanston which is in Cook County. Because we were focussing on the single-parent experience, the factor of geographical residence did not seem a major variable for this purpose.

We conducted a total of 14 depth interviews covering: (1) the nature of the child's mental retardation, (2) services which have been used and are expected to be used in the future, (3) how the current day or residential program was chosen, (4) satisfactions and dissatisfactions with these services, and (5) the effect of having a mentally retarded child upon the family. The interviews, ranging in length from two to six hours, were all tape recorded. The typed single-spaced transcripts range in length from 18 to 53 pages.

Review of the Literature and Identification of Major Subject Areas. A computerized review of the literature was conducted through Northwestern University Library Computer Assisted Information Service for a variety of descriptors related to mental retardation such as: exceptional child education, research and services, handicapped children, educable and trainable mentally handicapped, retarded children, autism, cerebral palsy, mongolism, epilepsy, developmental disability, regular class placement, institutionalized persons, learning difficulties, low achievers, residential programs, special education, parent education, community programs and involvement, normalization, labeling

(of persons), grouping (instructional purposes).

Hundreds of books, articles and reports were identified and their abstracts screened for reference to parental or community attitudes and involvement. These relevant publications were obtained and 47 pages of brief notes compiled listing major concepts, theoretical relationships, and empirical findings.

Data from the review of the literature was integrated with that from the depth interviews to develop a seven-page list of major subject areas and an item pool, 87-page list of related potential items for the questionnaire.

Development of the Survey Questionnaire. The computerized review of the literature and open-ended depth interviews with parents were used to construct a mail survey questionnaire. The questionnaire was pretested with 66 families of children attending three schools for mentally retarded children in Evanston, Illinois. The City of Evanston, in Cook County, was selected for the pretest because of its proximity to Northwestern University and to Lake County.

The questionnaire was sent home in the children's lunch boxes along with a cover letter from the director (at the two private schools) or president of the parents' association (at the public school). Parents were asked to return the completed questionnaire in an attached self-addressed stamped envelope, and were given about a week to do so. The participating schools and return rates were as follows: Park School, Public School District #65, 32/59 = 54%; Rimland School for Autistic Children, 14/19 = 74%; and, Shore School (North Shore

Association for the Retarded), 18/42 = 43%. An additional two questionnaires were returned on which the name of the school was not specified for an overall response rate of 66/120 = 55%.

The returned questionnaires were coded and keypunched and a file defined for statistical analysis of the data with the Statistical Package for the Social Sciences (SPSS) system of computer programs. The data was cleaned by eliminating out-of-range errors and performing a series of contingency checks. An examination of the frequency distributions as well as the respondents' written comments revealed ambiguities in question wording, and difficulties with format. Changes were accordingly made for the final target population in the Lake County mail survey questionnaire.

Following revisions based upon the pretest results, a 57-page mail survey questionnaire was developed for the Lake County population. Structured closed-ended questions were designed to provide data regarding:

--the manner in which parents first discovered that their child was mentally retarded;

--the availability of extended family and community support networks;

--the nature of the disability, skill levels, and kinds of limits the children have;

--the manner in which parents successfully or unsuccessfully secure the community services;

--the current professional intervention encountered and its perceived value;

--parents' attitudes regarding the direct services currently used for their children;

--parental involvement in their children's educational programs and parents' organizations;

--parents' opinions about general policy directions for the provision of services in their community.

The Research Population. The population was defined as Lake County, Illinois, parents of developmentally disabled children ages 0-21 who receive services in Lake County. For the purposes of the study, developmentally disabled was defined as children handicapped by mental retardation, cerebral palsy, epilepsy, autism, or multiple handicaps involving one of the foregoing, and whose handicap required more than 50 percent time in special education programs. The stipulation regarding percent of time in special education was imposed to reduce the number of so-called "six-hour retarded children." The "six-hour retarded child" is a phrase coined to depict the culturally deprived child whose developmental delays occur only in the area of school performance (Mercer, 1973a). Our definition restricted the families, insofar as possible, to those having children with physiologically-based disabilities. Therefore, all the children in the study had severe enough forms of mental retardation that they would not be classified in the "mild" or "educable" range of mental retardation.

Data Collection. Because present federal law (P.L. 94-142) requires that all mentally retarded children between 3 and 21 years must receive a free appropriate education, and because early intervention programs provide services to the 0 to 3 year old age group, records on all children are kept by special education public and private agencies.

Because of school administrators' interpretation of regulations

governing rights of privacy, mailings requesting parents to consent to participate in the study went out through the educational facilities serving Lake County: three special education school districts, a state residential facility, a federally funded early intervention program, and six private facilities. Cover letters were included with the signature of the superintendent, principal, or director. Due to the low percentage of consents received after the first mailing (37.7 percent), these educational facilities also conducted a follow-up mailing. Essentially the researchers became a third party to their own research project. No listing of the population was available for follow-ups to estimate the bias introduced by non-respondents. In future studies, every effort should be made to avoid the use of consent forms mailed prior to questionnaire distribution and to obtain a listing of the population utilized for sampling purposes.

The 57-page questionnaire in booklet form was mailed to each family (61.0 percent) who finally consented to participate. Included with each questionnaire mailed was a return postcard which respondents were asked to mail separately at the same time they mailed the completed questionnaire. The questionnaires themselves were filled in and returned anonymously. A follow-up letter with a second return postcard was sent approximately one month later if we had not received a postcard notifying us of its return before that time. These procedures resulted in the return of 330 completed questionnaires (43.9 percent of the families identified and contacted; 72.1 percent of the families who consented to participate).

By the time the four mailings were conducted (two for informed

consents and two for the mail survey questionnaire) time and money allocated for data collection were exhausted. Names and addresses were available for those families who consented and then did not respond, but the budgetary constraints precluded telephone follow-ups with this group. With the initial mailing of consent forms occurring in January 1978, the follow-up mailings to consenting families who had not returned questionnaires was not completed until June 1978, at the end of the school year.

Consent and Response Rates. Consent and response rates varied depending upon the type of special education facility in which a child was enrolled (see Table II). The lowest rate of questionnaire completed occurred in the urban special education school district (Waukegan, Illinois), whether completion rates are calculated on the basis of families originally contacted or on the basis of families who consented to participate in the survey.

Demographic questionnaire items made it possible to compare seven characteristics of respondents to 1970 census characteristics of the entire Lake County population as well as of the city of Waukegan subpopulation (see Table III). Waukegan contains a larger concentration of low income families and of minorities than is true for the county as a whole, which probably accounts for its lower response rate. In general, the sample seems to be fairly representative of the Lake County population in terms of range of social and economic characteristics, except to overrepresent minorities, high school graduates and single-parent families.

Table II

Lake County, Illinois Families With Mentally Retarded Children 21 Years of Age and Under--
Identified, Consenting to Participate in Survey, and Returning Survey Questionnaire

Educational Facility	Families contacted (N)	Families who consented to participate (N)	Families who consented to participate % of those contacted	Families who returned surveys (N)	Families who returned surveys % of those contacted	Families who returned surveys % of those consenting
Special Education School District:						
Waukegan	(274)	(141)	51.5%	(73)	26.6%	51.8%
NSSED*	(77)	(45)	58.4	(35)	45.5	77.8
SEDOL**	(214)	(154)	72.0	(118)	55.1	76.6
State Residential Facility						
Waukegan Developmental Center	(29)	(21)	72.4	(18)	62.1	85.7
Federally Funded Early Intervention						
Lake-McHenry Regional Program	(70)	(39)	55.7	(33)	47.1	84.6
Private Facilities						
Countryside	(10)	(5)	50.0	(5)	50.0	100.0
Glenkirk	(7)	(6)	85.7	(6)	85.7	100.0
Grove	(22)	(22)	100.0	(19)	86.4	86.4
Klingberg	(2)	(2)	100.0	(1)	50.0	50.0
Lambs	(1)	(1)	100.0	(1)	100.0	100.0
Moraine	(3)	(3)	100.0	(2)	66.7	66.7
Out-of-County Facilities Identified through Special Education School Districts						
Waukegan	(2)	(2)	100.0	(1)	50.0	50.0
NSSED*	(15)	(10)	66.7	(7)	46.7	70.0
SEDOL**	(25)	(7)	28.0	(5)	20.0	71.4
Missing Data				(6)		
TOTALS	(751)	(458)	61.0%	(330)	43.9%	72.1%

*Northern Suburban Special Education District
**Special Education District of Lake County

Table III

Comparison of Respondents' Characteristics with 1970 Census Data for Lake County, Illinois and Waukegan Populations, and for Waukegan Black and Spanish-Language Subpopulations

	Lake County		Waukegan					
			Total Population		Blacks		Spanish Language	
	Families Responding	1970 Census	Families Responding	1970 Census	Families Responding	1970 Census	Families Responding	1970 Census
1) Percent Minority								
Black	11.3	5.2	25.5	12.8	---	---	---	---
Spanish Language[a]	3.1	2.9	10.2	7.2	---	---	---	---
2) Percent living in county/community for 5 or more years[b]	66.1	64.4	72.2	79.8	64.0	76.8	70.0	70.4
3) Mdn school years completed[c]	12.0	12.5	12.0	12.2	12.0	10.4	8.0	8.4
4) Percent high school graduates[d]	80.4	63.3	68.0	56.7	60.0	33.7	20.0	24.1
5) Mdn family income								
(1969)	---	$13,009	---	$11,478	---	$8,000	---	$8,641
(1978)	$17,823	---	$15,632	---	$10,333	---	$13,500	---
6) Percent school-aged children in single-parent families/ households[e]	13.6	11.3	22.7	15.9	52.0	34.8	30.0	8.1
7) Percent mothers of school-aged children in labor force[f]	47.9	40.4	58.1	50.3	60.0	70.9	50.0	44.9
N =	(330)		(98)		(25)		(10)	

[a]Respondents identified themselves as "Latino"; 1970 Census reports figures for Spanish language minority group.

[b]Respondents identified length of time they had lived in their current city or town of residence; the Census categories of "living in same house" and "different house, same county" were combined.

[c]Respondents identified level of schooling completed for child's mother; Census data reports figures for all adults 25 years of age and older.

[d]Respondents reported for child's mother; Census data for all adults 25 years of age and older.

[e]Respondents reported for children 21 years of age and under; Census data reports figures for children under 18 years of age.

[f]Respondents reported for children 21 years of age and under; Census data reports figures for women with own children 17 years of age and under.

C. Variables and Methods

Questionnaire items were developed as indicators of the conceptual framework summarized in Table I. The items were factor analyzed using the principal factoring with iteration method and varimax orthogonal rotation. Items measuring community involvement and advocacy were analyzed for the entire sample, as were items measuring the stress experienced by mothers as a subset of the family career variables. Separate factor analyses were conducted for items measuring the stress experienced by both parents only for that subsample of currently married respondents with the mentally retarded children living at home. Two other separate factor analyses were also conducted for subsamples of the population as appropriate: items assessing the children's characteristics were analyzed only for families with the children living at home; and items assessing extended family support from grandparents were analyzed only for families with the children living at home in which at least one grandparent was living. Simple additive indexes were constructed on the basis of the patterning of variables identified by the factor analyses.

The variables used in this paper are explained below. Table IV lists the variables, with the exception of alternative family career stage measures (see Table XI), and provides means and standard deviations for the total sample and each subsample.

Residential and Vocational Planning (Dependent Variables). Project Residential Future is respondents' planning for future residential care for their children. Responses were coded: (1) have not

Table IV

Means and Standard Deviations of Variables

	Entire Sample		Respondents with Child at Home		Respondents with Child at home and Grand parent(s) living		Married Respondents with Child at Home	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Residential and Vocational Planning								
Project Residential Future	1.81	.80	1.66	.72	1.68	.71	1.68	.72
Project Institutionalization at Age 2.	2.61	1.29	2.38	1.16	2.38	1.18	2.42	1.16
Project Sheltered Work at Age 21	2.31	.85	2.23	.86	2.21	.87	2.26	.86
Pro-Mainstreaming	20.06	6.97	20.76	6.95	20.93	7.00	20.47	6.87
Family Demographics								
Family Income	7.82	2.17	7.77	2.24	7.84	2.23	8.26	1.78
Race, White	.85	.36	.83	.37	.85	.36	.90	.30
Mother's Education	3.49	1.25	3.45	1.23	3.52	1.21	3.56	1.22
Grandparent(s) Living	.85	.36	.85	.36	N.A.	N.A.	.87	.34
Currently Married	.87	.34	.87	.34	.89	.32	N.A.	N.A.
Child at Home	.88	.32	N.A.	N.A.	N.A.	N.A.	N.A.	N.A.
Family Career								
Mother's Age	39.02	9.42	38.55	9.39	36.92	8.54	38.99	9.39
Mother's Stress	6.03	2.88	5.77	2.73	5.81	2.80	N.A.	N.A.
Parents' Stress	N.A.	N.A.	N.A.	N.A.	N.A.	N.A.	3.12	1.79
Parents' Time Constrained	N.A.	N.A.	N.A.	N.A.	N.A.	N.A.	6.68	2.79
Community Involvement and Advocacy								
Community Acceptance	25.85	7.16	26.77	6.72	26.76	6.82	26.77	6.77
Friend's Advice	9.53	2.39	9.51	2.30	9.58	2.27	9.50	2.30
Feeling Excluded	8.09	3.91	8.09	3.83	7.83	3.68	8.04	3.81
Political Participation	3.32	1.26	3.30	1.24	3.35	1.27	3.29	1.27
Child's Characteristics								
Low Cognitive Skills	N.A.	N.A.	11.48	4.38	11.85	4.25	11.64	4.32
Low Social Skills	N.A.	N.A.	27.95	11.80	29.07	11.97	27.94	11.74
Child's Sex, Male	N.A.	N.A.	.58	.49	.58	.49	.58	.49
Child's Age	N.A.	N.A.	11.00	5.75	10.39	5.77	11.04	5.83
Extended Family								
Grandparents Accept Child	N.A.	N.A.	N.A.	N.A.	6.61	2.91	N.A.	N.A.
Grandparents Support Parents	N.A.	N.A.	N.A.	N.A.	8.91	1.59	N.A.	N.A.
N . . .	330		291		248		253	

NOTE: N.A. = not applicable; variables explained in text.

considered future residential care; (2) have considered the general idea; (3) have specific plans for residential care.

Project Institutionalization at Age 21 is child's living situation perceived as appropriate at age 21. Responses were coded in terms of the amount of structured supervision provided in the living situations: (1) Living on own or with friends; (2) with parent(s) at home; (3) supervised apartment house unit; (4) private residential facility; (5) a public residential facility.

Project Sheltered Work at Age 21 is child's work situation perceived as appropriate at age 21. Responses were coded in terms of the amount of structured supervision provided in the work situation: (1) regular job in the community; (2) a supervised job in a special business program (for example, in a hospital, restaurant or motel); (3) a job in a sheltered workshop or a work activities program.

Pro-Mainstreaming is an index which measures favorability of respondents' beliefs about mainstreaming. The value for each respondent is obtained by summing responses to eight items covering beliefs about: own child's ability to get along socially if all other children in the program were normal; own child learning more in special education classes than would be possible in regular classes; own child doing better in a special recreation program than in a regular program; mainstreaming as an excuse for cutting back funds for special education; importance of own child being assured of a secure lifelong placement; appropriateness of supervised living situation for own child; appropriateness of supervised work situation for own child; and appropriateness of mainstreaming own child educationally in community. A score of

one on each item represented the least favorable attitude about mainstreaming and a score of five the most favorable attitude, giving the index a range of 8 to 40.

Family Demographics. Family Income is the present (1978) yearly family income before taxes including dividends, interest, salaries, wages, pensions and all other income. Ten income categories were provided ranging from less than $2,000 to $25,000 and over.

Respondent's Race is a dummy variable set equal to 1 if the respondent is white, 0 if otherwise.

Mother's Education is the level of formal schooling completed by the respondent measured in terms of seven categories ranging from elementary school or less to advanced postgraduate degree.

Grandparent(s) Alive is a dummy variable set equal to 1 if at least one of the child's grandparents is alive, and 0 if all are deceased.

Marital status is a dummy variable set equal to 1 if the respondent is currently married, 0 if otherwise.

Child at Home is a dummy variable set equal to 1 if the mentally retarded child lives at home, 0 if otherwise.

Family Career. Mother's Age is respondent's age in years.

Mother's Stress is an index which measures the amount of stress the respondent reports associated with the mentally retarded child. The value for each respondent is obtained by summing responses to three items covering the mother's reports of: becoming so frustrated by problems caused by the disability that she wished the child would die;

feeling trapped at home because of the child; and wishing she could go out more without the child. The value was obtained by summing scores from three Likert scale attitude questions, giving the index a range of 3 to 15.

Parents' Stress is an index which measures the feelings of stress reported for both parents by married respondents. The value is obtained by summing responses to two parallel Likert scale items, one for respondent and one for husband's reported feelings: "Sometimes I've (my husband has) become so frustrated by problems caused by the disability that I've (he's) wished our child would die." The index has a range of 2 to 10.

Parents' Time Constrained is an index which measures married respondents' reported time constraints. The value for each married respondent is obtained by summing scores to three Likert scale items: feeling trapped at home because of the child; wishing she could go out more without the child; and satisfaction with the amount of time spent alone with husband. The index has a range of 3 to 15.

Community Involvement and Advocacy. Community Acceptance is an index which measures perceived acceptance by neighbors of the respondent's mentally retarded child at different stages in life in the following situations: as a friend for their own children of the same age; of the opposite sex; as a classmate at the same school; as a member of a social club; as a guest in their own homes; as a neighbor living in a community living facility upon reaching adulthood; and visiting respondents when child is at home. The value for each

respondent is obtained by summing scores from seven Likert scale items, giving the index a range of 7 to 35.

Friends' Advice is an index which measures frequency of consulting friends and family members for advice about the mentally retarded child. The value for each respondent is obtained by summing scores to three Likert scale items: confiding in friends or relatives when worried; talking to other parents with mentally retarded children; and talking to other family members or friends when making a serious decision. The index has a range of 3 to 15.

Feeling Excluded from parent groups is an index which measures respondents' reasons for not attending meetings with other parents of mentally retarded children: parents meetings are a waste of time because real decisions are made elsewhere; because they never seem to talk about things related to respondent's child; because people who run the meetings do not seem to care about the respondent; and because respondent does not feel comfortable with the kind of people who attend. The value for each respondent is obtained by summing scores to four Likert scale items, giving the index a range of 4 to 20.

Political Participation is an index which measures involvement in two types of parent groups: governing or advisory board (dealing with the administration of an organization or facility for the mentally retarded), and a political advocacy group (working to expand options and services for the mentally retarded). The value for each respondent is obtained by summing scores on two 3-point questions, giving the index a range of 2 to 6. A score of 1 on each item indicates the respondent has not participated and does not plan to, 2 that the

respondent has not participated but would like to, and 3 that the respondent has participated.

Child's Characteristics. Low Cognitive Skills is an index which measures the mentally retarded child's reported abilities in the following areas: reads simple sentences, writes simple sentences, and rides public transportation alone. The value for each respondent with the child living at home is obtained by summing scores on the three Likert scale items, each ranging from "handles easily" to "child cannot do." The index has a range of 3 to 15.

Low Social Skills is an index which measures reported level of disabilities on twelve items: diagnosis as mild, moderate, severe, or profound; self-care activities (for example, goes to toilet without help, gets dressed, feeds self); undertsands when spoken to; speaks clearly enough to be understood; organizes activities for self (for example, turns on TV, picks up book or magazine, suggests playing a game); self-help skills (for example, shops, picks out right clothing for weather or event, prepares some meals, handles money); shakes hands when meeting someone for the first time; greets people by saying hello; eats properly; speaks at the proper volume; looks at people when spoken to; and knows how to behave properly in different settings. The index has a range of 12 to 60 with a high score representing the lowest level of social skills.

Child's Sex or sex of mentally retarded child is a dummy variable set equal to 1 if the child is male, 0 if female.

Child's Age is mentally retarded child's age in years.

Extended Family. Grandparents Accept Child is an index which measures respondents' perception of the grandparents' acceptance of the mentally retarded child. The value for each respondent with at least one of the child's grandparents living is obtained by summing scores on two Likert scale items: grandparents do not see anything wrong with the child; and grandparent(s) would want the child to live with them if something happened to the parent(s). The index has a range from 2 to 10.

Grandparents Support Parents is an index which measures grandparents' perceived support of the parent(s). The value for each respondent with at least one of the child's grandparents living is obtained by summing scores on two Likert scale items: grandparents think respondent is handling the situation well; and respondent thinks contact with grandparents is less than it would be if the child was normal. The index has a range from 2 to 10.

Alternative Family Career Stage Variables. Preschooler is a dummy variable scored 1 if the mentally retarded child is five years of age or younger, and 0 if otherwise.

Adolescent is a dummy variable scored 1 if the mentally retarded child is between the ages of thirteen and eighteen inclusive, and 0 if otherwise.

Transition to young adulthood is a dummy variable scored 1 if the mentally retarded child is between the ages of nineteen and twenty-one, inclusive, and 0 if otherwise.

Youngest's Age is the age of youngest child in family in years.

CHAPTER III. RESULTS

The analyses consist of a series of ordinary least squares regression analyses to evaluate the overall contribution of family demographics, family career, community involvement and advocacy, child's characteristics, and extended family to residential and vocational planning. Tables V and VI present the intercorrelations for the variables used in the regression analyses for the total sample and three subsamples--respondents with children at home, respondents with children at home and grandparents living, and currently married respondents with children at home.

The subsamples were derived to test the hypotheses within those segments of the population where the family structure would be most likely to optimize the support assumed prerequisite to normalization. That is, family and community support variables, as they interact with the mentally retarded children's characteristics to explain parents' planning, can be assessed most effectively in those families where the children are living at home, and where a husband and/or other extended family (grandparents) are available. By the time this study was conducted in 1978 it was very difficult to place or maintain in an institutional setting any child except for the most severely disabled; the prognosis for such children achieving residential or vocational autonomy in the future would be minimal. For those children living at home, the two-parent family is assumed to be a more effective socializing agency than the one-parent family, and the extended family to be more effective

Table VI

Correlations for Variables Used in Regression Analyses for Respondents With Mentally Retarded Children Living at Home: Respondents with Grandparent(s) Living (Above Diagonal, N = 248); Married Respondents (Below Diagonal, N = 253)

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23
Residential and Vocational Planning																							
1. Project Residential Future	--	.48	.38	-.38	.10	.24	.19	NA	.04	.13	.31	NA	NA	-.35	.23	-.08	.08	.18	.14	-.14	-.11	.04	.18
2. Project Institutionalization at Age 21	.54	00	.52	-.54	.24	.12	.20	NA	.12	.18	.40	NA	NA	-.39	.25	-.13	.26	.19	.17	-.02	-.16	.20	.35
3. Project Sheltered Work at Age 21	.37	.52	--	-.61	.16	.09	.10	NA	.10	.36	.28	NA	NA	-.46	.13	.06	.12	.23	.14	-.07	-.27	.07	.44
4. Pro-Mainstreaming	-.42	-.54	-.63	--	-.12	-.11	-.04	NA	-.11	-.30	-.34	NA	NA	.43	-.12	-.04	-.13	-.20	-.17	.07	.25	-.12	-.31
Family Demographics																							
5. Family Income	.12	.17	.11	-.05	--	.37	.43	NA	.55	.17	.16	NA	NA	-.09	-.003	-.09	.06	.14	-.02	.09	-.08	-.13	.14
6. Race, White	.23	.11	.04	-.03	.25	--	.28	NA	.41	.02	.06	NA	NA	-.03	.08	-.10	-.02	.28	.07	-.13	.09	-.16	.02
7. Mother's Education	.14	.12	.05	-.004	.39	.18	--	NA	.26	.02	.19	NA	NA	-.11	.07	-.06	.10	.26	.16	.03	.20	-.08	.12
8. Grandparent(s) Alive	.05	.03	-.05	.07	.04	.02	.17	--	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
9. Currently Married	NA	NA	NA	NA	NA	NA	NA	NA	--	.19	.14	NA	NA	-.05	-.02	-.03	.04	.10	-.04	.03	-.03	-.07	.10
Family Career																							
10. Mother's Age	.11	.18	.35	-.28	.06	-.03	-.11	-.03	NA	--	.15	NA	NA	-.14	-.01	.05	.07	-.19	-.42	-.04	-.62	.09	.28
11. Mother's Stress	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	--	NA	NA	-.37	.15	.08	.08	.15	.19	-.01	-.02	.24	.29
12. Parents' Stress	.22	.29	.18	-.18	.09	-.06	.16	.10	NA	.003	NA	--	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
13. Parents' Time Constrained	.31	.34	.21	-.20	.07	.03	.11	.07	NA	-.02	NA	.47	--	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
Community Involvement and Advocacy																							
14. Community Acceptance	-.34	-.35	-.47	.45	-.05	.01	-.06	-.05	NA	-.10	NA	-.29	-.34	--	-.10	-.09	-.14	-.19	-.25	-.11	.18	-.21	-.42
15. Friends' Advice	.23	.23	.15	-.11	.05	.14	.03	.08	NA	-.03	NA	.04	.13	-.12	--	-.14	.10	.18	.10	-.02	.12	-.11	.05
16. Feeling Excluded	-.12	-.15	.05	-.02	-.10	-.11	-.10	-.17	NA	.06	NA	.01	.02	-.07	-.16	--	-.10	-.15	-.01	.06	-.13	.23	.02
17. Political Participation	.14	.27	.16	-.15	.08	.01	.15	.15	NA	.04	NA	.05	.08	-.18	.15	-.18	--	.06	-.05	.07	-.07	.03	.13
Child's Characteristics																							
18. Low Cognitive Skills	.21	.17	.22	-.20	.06	.19	.20	.22	NA	-.22	NA	.10	.21	-.16	.24	-.17	.13	--	.54	.004	.46	-.09	.20
19. Low Social Skills	.17	.17	.11	-.16	-.05	.02	.17	.21	NA	-.43	NA	.19	.30	-.22	.11	-.02	.01	.53	--	.02	.52	.05	.10
20. Child's Sex, Male	-.15	-.01	-.07	.07	.13	-.10	.03	.03	NA	-.02	NA	.02	-.01	-.09	-.03	.08	.05	-.02	.001	--	.003	-.03	-.04
21. Child's Age	-.15	.19	-.30	.27	-.06	.06	.25	.26	NA	-.65	NA	.06	.07	.18	.09	-.15	-.03	.43	.52	.01	--	.06	.12
Extended Family																							
22. Grandparents Accept Child	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	--	-.20
23. Grandparents Support Parents	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	--

NOTE: NA = not applicable; variables explained in text.

than the isolated nuclear family. Selecting subsamples to examine types of intact families separately enables us to study the factors of interpersonal support as they relate to planning for normalized outcomes.

Family Demographics. My hypotheses were based upon Farber's (1968: 154, 197; 1975:259) prediction that the higher the socioeconomic status of families, the greater the emotional impact of a mentally retarded child would be. Families with higher socioeconomic status were assumed to hold higher expectations for children's performance and achievement, and therefore more likely to extrude children who could not meet these expectations. These bivariate predictions were supported (see Tables V and VI). On the other hand, hypotheses derived from the prediction that intact extended families would be better able to cope with a mentally retarded member were generally not supported. Neither having grandparents alive nor marital status was significantly correlated with planning.

For the total sample (see Table VII), income and race--two of the three measures of socioeconomic status--were statistically significant in accounting for parents' planning, but in quite different ways. Higher income contributed to parents' planning for more restricted residential and vocational outcomes at the time of transition to adulthood at age 21. Whites were more likely than minorities to have made specific plans for future residential care while being less likely to support mainstreaming. Whites seem less likely to envision a supportive family and community environment over their children's total life cycles, and higher family income seems to provide the means with which

to plan for protected adult environments. As expected, families whose children are living at home are less likely to project a residential future and more likely to favor mainstreaming than are families with children already in residential care. What is surprising perhaps is the finding that the mentally retarded children's place of residence--at home or in an institutional setting--does not contribute to parents' assessment of appropriate work setting at age 21. This finding of no statistically significant association between place of residence and occupational planning does, however, validate the assumption underlying the sampling procedures, i.e. all the children in the sample are mentally retarded by physiological (and not merely cultural or social) criteria. They are not so-called "6-hour retarded" children, mentally retarded only by educational criteria (Mercer 1973b), who will leave school for regular jobs in the community.

In the subsequent subsample analyses, appropriate independent variables were introduced which were expected to account for parents' planning. When the subsample of children at home (see Table VIII) was analyzed, the selection variable Child at Home was deleted and independent variables measuring child's characteristics were added. When the subsample of children at home and grandparents alive (see Table IX) was analyzed the selection variable Grandparent(s) Living was deleted and independent variables measuring the kinds of extended family support were added. The addition of these variables seems to account for the influence of family income on parents' planning for sheltered work at age 21 and for the influence of respondent's race on parents' support of mainstreaming. However, higher family income continues to

Table VII

Regression Analysis of Family and Community Variables on Residential and Vocational Planning for Total Sample (Reported Coefficients are Beta Weights, N = 330)

	Project Residential Future	Project Institutionalization at Age 21	Project Sheltered Work at Age 21	Pro-Mainstreaming
Family Demographics				
Family Income	-.01	.13**	.10*	-.04
Race, White	.18***	.03	.08	-.10*
Mother's Education	.01	.01	-.01	.07
Grandparent(s) Living	.09*	.03	.05	-.02
Currently Married	-.04	-.06	-.07	-.004
Child at Home	-.39***	-.34***	-.06	.09*
Family Career				
Mother's Age	.11**	.11**	.30***	-.22***
Mother's Stress	.17***	.24***	.10*	-.19***
Community Involvement and Advocacy				
Community Acceptance	-.19***	-.17***	-.33***	.27***
Friend's Advice	.09*	.13**	.13**	-.10*
Feeling Excluded	-.07	-.09*	.03	-.03
Political Participation	.005	.09*	.02	-.06
R^2 =	.44	.45	.35	.31

*p < .05; **p < .01; ***p < .001

predict institutionalization at age 21 and whites continue to be more likely than minorities to plan for future residential care. Both findings are consistent with Farber's predictions.

When the subsample of currently married respondents with children at home (see Table X) was analyzed, the selection variable Currently Married was deleted and measures of stress in husband-wife relations were substituted for measures of stress in mothers. In order to retain a reasonable number of cases, the structural variable Grandparent(s) Living was retained rather than the interpersonal extended family support variables. Only race remained statistically significant, and only in the case of whites being more likely to plan for future residential care.

In general, demographic variables measuring socioeconomic status and family structure are not important predictors of parents' planning relative to interpersonal family and community support variables and child's characteristics.

Family Career. Birenbaum (1971) found that families' careers can be brought to a halt by the inability of mentally retarded members to assume age-appropriate roles in progressive stages. Therefore, I predicted that older parents and parents experiencing more stress were more likely to plan for restricted residential and vocational settings and were less likely to be in favor of mainstreaming. The bivariate relationships predicted were supported (see Tables V and VI).

In the regression analyses, both respondent's age and stress were statistically significant in accounting for parents' planning on

Table VIII

Regression Analysis of Family, Community and Child Variables on Residential and Vocational Planning for Respondents With Children at Home (Reported Coefficients are Beta Weights, N = 291)

	Project Residential Future	Project Institutionalization at Age 21	Project Sheltered Work at Age 21	Pro-Mainstreaming
Family Demographics				
Family Income	-.04	.14**	.08	-.03
Race, White	.21***	.03	.02	-.06
Mother's Education	.07	.06	.03	.03
Grandparent(s) Alive	.08	-.04	.01	.01
Currently Married	-.06	-.06	-.06	-.02
Family Career				
Mother's Age	.05	.07	.28***	-.20**
Mother's Stress	.21***	.27***	.06	-.15**
Community Involvement and Advocacy				
Community Acceptance	-.17**	-.11*	-.25***	.18***
Friend's Advice	.11*	.14**	.09*	-.07
Feeling Excluded	-.10*	-.14**	.06	-.04
Political Participation	.01	.14**	.03	-.06
Child's Characteristics				
Low Cognitive Skills	.06	.06	.24***	-.21***
Low Social Skills	.14*	.23***	.15**	-.21***
Child's Sex, Male	-.10*	-.02	-.11**	.11*
Child's Age	.22**	.28***	.24***	-.28***
R^2 =	.29	.38	.42	.37

*p < .05; **p < .01; ***p < .001

Table IX

Regression Analysis of Family, Community and Child Variables on Residential and Vocational Planning for Respondents With Children at Home and Grandparent(s) Living
(Reported Coefficients are Beta Weights, N = 248)

	Project Residential Future	Project Institutionalization at Age 21	Project Sheltered Work at Age 21	Pro-Mainstreaming
Family Demographics				
Family Income	-.04	.14*	.05	-.004
Race, White	.20**	.03	.004	-.05
Mother's Education	.12*	.07	-.01	.07
Currently Married	-.10	-.04	-.02	-.02
Family Career				
Mother's Age	.03	-.01	.22***	-.19**
Mother's Stress	.17**	.19***	.04	-.14**
Community Involvement and Advocacy				
Community Acceptance	-.22***	-.09	-.22***	.18**
Friend's Advice	.15**	.19***	.07	-.06
Feeling Excluded	-.08	-.16**	.05	-.02
Political Participation	.01	.15**	.03	-.06
Child's Characteristics				
Low Cognitive Skills	.05	.05	.19**	-.17**
Low Social Skills	.10	.18**	.17**	-.24***
Child's Sex, Male	-.13**	-.03	-.09*	.08
Child's Age	.21**	.28***	.25***	-.29***
Extended Family				
Grandparents Accept Child	.04	-.11*	-.18***	.04
Grandparents Support Parents	-.005	-.17***	.05	.01
R^2 =	.30	.42	.42	.37

*$p < .05$; **$p < .01$; ***$p < .001$

Table X

Regression Analysis of Family, Community and Child Variables on Residential and Vocational Planning for Currently Married Respondents With Child at Home (Reported Coefficients are Beta Weights, N = 253)

	Project Residential Future	Project Institutionalization at Age 21	Project Sheltered Work at Age 21	Pro-Mainstreaming
Family Demographics				
Family Income	.01	.06	.06	-.02
Race, White	.17**	.07	-.01	-.005
Mother's Education	.09	.04	.02	.01
Grandparent(s) Alive	.01	-.01	.02	.03
Family Career				
Mother's Age	.02	.08	.28***	-.17**
Parents' Stress	.08	.15**	.05	.01
Parents' Time Constrained	.13*	.14*	-.02	-.12*
Community Involvement and Advocacy				
Community Acceptance	-.17**	-.10	-.30***	.25***
Friend's Advice	.13*	.14**	.07	-.02
Feeling Excluded	-.09*	-.14**	.05	.01
Political Participation	.03	.16**	.05	-.06
Child's Characteristics				
Low Cognitive Skills	.09	.04	.23***	-.18**
Low Social Skills	.15*	.23***	.16**	-.21**
Child's Sex, Male	-.14**	-.01	-.10*	.08
Child's Age	.28***	.31***	.25***	-.29***
R^2 =	.32	.37	.43	.37

*p < .05; **p < .01; ***p < .001

all the dependent variables only for the total sample (see Table VII) before child's characteristics were taken into account. With child's characteristics entered into the regression equations for the subsample analyses however (see Tables VIII, IX and X) the relative importance of stress and age is quite different for residential planning than for vocational planning. Stress, whether experienced individually (see Tables VIII and IX) or in terms of relationships with spouses (see Table X), contributes to whether or not parents plan to institutionalize their children (to extrude them in Farber's [1968, 1975] phraseology). Age, but not stress, contributes to whether parents with children at home predict more restricted vocational settings at age 21. Age thus seems to be more a cross-sectional measure of the historical effect of parents' beliefs about possible employment opportunities for mentally retarded adults than to be a measure of anxiety associated with aging as the current literature suggests (Baroff, 1974:23; Ayrault, 1971: 165; Adams, 1972:115; Birenbaum and Seiffer, 1976:75).

Community Involvement and Advocacy. As described by Mechanic (1980:108, 110), personal and community supports are resources that families use to cope and to arrive at solutions about how to maintain family careers. Therefore I predicted that receiving advice from friends and political participation, would exert a conservative influence on parents' planning. Conversely, perceiving the community as accepting of mentally retarded individuals and feeling excluded from parents groups were hypothesized to be associated with planning less restrictive residential and vocational outcomes. The bivariate

relationships predicted were supported (see Tables V and VI).

In the regression analyses, the perceived acceptance of mentally retarded individuals contributed to all four dependent variables, parents' planning for less restricted residential and vocational settings as well as their support for mainstreaming. Receiving advice from friends, political participation, and not feeling excluded from parents' groups contributed to planning more restricted residential settings only. Community involvement seems to provide an informational rather than a supportive therapeutic function to families with mentally retarded children. Participation in a community social network provides parents with information necessary to make decisions concerning their children's futures but not the support needed to achieve more normalized outcomes. This indicates that involvement in community networks, whether informally with friends or more formally through parents' groups or political activities, is less important than perceived community acceptance in achieving less restrictive residential and vocational settings for mentally retarded adults.

Extended Family. Contrary to my predictions, when the bivariate correlations are examined (see Table VI) grandparents seem to exert a conservative influence whether they accept the mentally retarded child or support the parents. Grandparents do not seem to accept the children as "normal" as we had predicted, but to accept them as mentally retarded children who at an earlier point in their grandparents' lives would have been excluded from community activities and institutionalized.

When family, community and child variables are also controlled

in the regression analyses (see Table IX), grandparents' acceptance of the children and support for the parents are both associated with planning less restricted residential and vocational settings at age 21. In this sense grandparents do seem to function as resources for families, enabling more normalized outcomes.

Children's Characteristics. As the literature suggests (Carver and Carver, 1972:53; Farber, 1968:162; Mercer, 1966; Wing and Gold, 1979:106) the more severe the disability the more likely parents are to extrude mentally retarded children from their families. Farber (1968: 157) found that mentally retarded males seem to create greater stresses for their families than do females. Birenbaum (1971:56) found that stress increases with child's age as discrepancies between age-appropriate behavioral expectations and actual performance become greater. Hypotheses derived from these findings were generally supported by the bivariate correlations (see Tables V and VI) except that families with mentally retarded daughters were more likely to plan restricted residential settings. It may be that families feel more protective of mentally retarded daughters than of sons.

In the regression analyses (see Tables VIII, IX and X) families whose children have lower cognitive skills plan for more restricted vocational settings and are supportive of mainstreaming. Low cognitive skills do not affect residential planning on all four dependent variables. Apparently social disabilities are more important than cognitive disabilities in causing families to extrude their mentally retarded children.

Having mentally retarded daughters was a statistically significant predictor of parents' having made specific plans for residential care and parents' planning for more restricted vocational settings at age twenty-one. This refutes Farber's (1968:157) finding that males create greater stress in families causing them to be extruded more often than females but supports Bayley's (1973:154-157) finding that males tend to be employed in more normalized jobs in the community upon reaching adulthood.

Overall, the age of the mentally retarded child is the strongest contributor to predicting parents' planning for future residential and vocational settings. It is statistically significant (at the .01 level or less) for all four planning variables in all three subsample regression analyses. This finding strongly supports Birenbaum's (1971:56) finding that stress increases with the age of the mentally retarded children. Their inability to accept more responsibility in age-appropriate roles tends to halt family development through normative careers.

As seen in Table XI, I have developed two alternative hypotheses to age of mentally retarded child in order to explore further Birenbaum's finding of unfulfilled family careers.

The first tests a hypothesis that age as measured in life cycle stages would be a better predictor of parents' planning than age in years. Age in life cycle stages is measured by a series of dummy variables, Preschooler, Adolescent, and Transition, indicating divisions within the mentally retarded child's life cycle. The second tests a hypothesis that a measure of family career, operationalized by the age of the youngest child in the family would be a better predictor of

Table XI

Beta Coefficients and R^2's for Regression Analysis of Family, Community and Child Variables on Residential and Vocational Planning to Test Family Career Stage as Alternative Hypotheses to Child's Characteristics

Child at Home (N=291)	Project Residential Future	Project Institutionalization at Age 21	Project Sheltered Work at Age 21	Pro-Mainstreaming
Child's Age[a]	.22**	.28***	.24***	-.28***
R^2	.29	.38	.42	.37
Preschooler	-.01	-.13*	-.07	.22***
Adolescent	.03	-.08	.01	.01
Transition	.17**	.12*	.09	-.07
R^2	.29	.38	.40	.37
Youngest's Age	.20**	.25***	.16**	-.22**
R^2	.28	.37	.40	.36
Respondents with Child at Home and Grandparents Living (N=248)				
Child's Age[b]	.21**	.28***	.25***	-.29***
R^2	.30	.42	.42	.37
Preschooler	-.01	-.13*	-.08	.22***
Adolescent	-.06	-.08	.01	.04
Transition	.16**	.14**	.12*	-.10*
R^2	.31	.43	.41	.38
Youngest's Age	.18**	.24***	.18**	-.23**
R^2	.30	.42	.42	.36
Married Respondents with Child at Home (N=253)				
Child's Age[c]	.28***	.31***	.25***	-.29***
R^2	.32	.37	.43	.37
Preschooler	-.02	-.16**	-.08	.18**
Adolescent	.06	-.08	.03	-.03
Transition	.20**	.12*	.09	-.09
R^2	.31	.36	.41	.36
Youngest's Age	.20**	.24**	.20**	-.23**
R^2	.30	.35	.42	.36

*$p < .05$; **$p < .01$; ***$p < .001$

[a]Beta coefficients for other variables in regression analyses are reported in Table VIII.

[b]Beta coefficients for other variables in regression analyses are reported in Table IX.

[c]Beta coefficients for other variables in regression analyses are reported in Table X.

parents' planning than age of the mentally retarded child in years.

The entrance of each alternative hypothesis as substitutions for Child's Age into the three subsample regression analyses made no overall improvement in the R^2 coefficient nor in the Beta coefficients themselves. Therefore, I find no evidence to reject the original assumption that age of the mentally retarded child is as useful (or more useful) a predictor of parents' planning as is age of the mentally retarded child in life cycle stages or age of the youngest child in the family. The data do show support for the life cycle stage theory because changes in parents' planning are affected by life cycle stage. In general, parents of preschool (ages birth through five years) mentally retarded children are less likely to plan for restricted residential and vocational settings than parents of transition-age (ages nineteen to twenty-one years) mentally retarded young adults. Conversely parents of younger children are more likely to favor mainstreaming than parents of older children.

CHAPTER IV. DISCUSSION

In this final section of the thesis, three tasks are to be accomplished: one, summarization of the results; two, presentation of the implications of the results to the literature on families with mentally retarded children; and three, relationship of the results to current planning processes and political realities.

For families with mentally retarded children, the variables measuring family career and individual life cycle were among the strongest predictors of parents' planning for future residential and vocational services for their children (see Tables VI, VII and VIII). With increasing age mentally retarded children are unable to assume age-appropriate roles within the family (Birenbaum 1971) and community. With increasing age, their parents become less able to care for their children's needs. Alternative methods for measuring family career and individual life cycles (see Table IX) were equally significant for predicting parents' future planning.

As predicted by Farber's (1975) minimal adaptation theory, parents experiencing more stress individually and in their relationships with their spouses plan for future residential services more than parents experiencing less stress. The extension of Farber's minimal adaptation theory to extended family members was supported. Extended family, as measured by grandparents' support, was found to contribute to parents' ability to cope with their mentally retarded children at home. Families with grandparents' support were less likely to have

planned for restricted residential and vocational settings.

It was hypothesized that community support, as measured by parents' involvement in formal and informal support groups, would help parents cope with their mentally retarded children at home. While community support variables were highly significant predictors, subsample analyses showed that community support tends to function as an informational resource rather than as a supportive therapeutic resource.

Family demographics, usually the staples of social science research, were generally not associated with parents' future plans, especially in the subsample analyses as child's characteristics were entered into the regression equations.

A. Implications for Theory

Families with mentally retarded children have been the subjects of sociological research since Tizard and Grad's (1961) study of families in Great Britain during the 1950's. Almost concurrently, the study of families with mentally retarded children in the United States was begun by Farber (1968). Each study spawned different lines of research (Rowitz, 1974).

Western European studies following Tizard and Grad (1961) were products of National Health services and therefore oriented towards understanding the different types of persons who utilize government-provided services. Thus research was used to provide information on the characteristics of persons and their families and the services they use.

Farber (1968) was concerned with families' adaptations to

having a mentally retarded child. Rowitz (1974) relates that Farber developed a conceptual model "to define different types of family organization which affect marital integration and severity of family crisis for parents of (mentally) retarded children."

The present study combines these two perspectives by using Farber's conceptual model of family adaptations as applied to a specific service utilization situation--parents' planning for future residential and vocational service use by their mentally retarded children. My research model uses a developmental framework combining individual life cycle stages and family careers as variables measuring family adaptations to mentally retarded children. The idea was suggested by Birenbaum's (1971) application of Farber's theory in the study of mentally retarded children in the home and family life cycle. My basic premise is that predictable changes in the life course of individuals and families can be used to understand characteristics of service use and plans for future service use by families with mentally retarded children.

In addition, the present study also builds in the concept of social embededness because decision-making by parents does not take place in the vacuum of the nuclear family unit. Personal and community support systems are resources that families use to live their everyday lives. Parents' decision-making, therefore, occurs within consideration of these community networks.

Research findings support Farber's model that increased stress within the family caused by the presence of a severely mentally retarded child at home is associated with extrusion (in this study,

planned extrusion) of the child from the home. These findings are the first empirical support of the minimal adaptation theory. What is significant is that the data seem to support the minimal adaptation theory in the absence of the more general theory of family types, suggesting that the more specific theory of minimal adaptation may be applicable to other more general theories, such as the theory of family careers espoused in this research. Further subsample analyses show that it is not merely stress which explains planning behavior, but a host of other factors.

Specifically, measures of individual life cycle and family career are strong predictors of parents' planning for future services supporting Birenbaum's findings. The age of the mentally retarded child is the single most important factor. Other characteristics of the child, such as social and cognitive skills, significantly predict parents' planning behavior. The findings that social disabilities are more important than cognitive disabilities in parents' planning behavior supports the literature (for example, Baller, Charles and Miller, 1967; Brolin, 1976; Cobb, 1972; Edgerton and Bercovici, 1976; and Katz, 1968) which found that social rather than physical impairments or deficits are more important in the adjustment of mentally retarded adults in the community. Families' involvement in personal and community support networks were statistically significant predictors of parents' planning for residential services. While family involvement in support networks seems to provide parents with needed information for residential placement rather than therapeutic support for maintaining the child at home, it is parents' perceptions of the community's acceptance of their

child which more strongly predicts parents' planning for both future residential and vocational settings.

The findings presented open an arena for more detailed research into the characteristics of families utilizing services for their mentally retarded children. It is suggested that further studies develop more sophisticated measurements of the interaction of the family career and individual life cycle concepts. Suelzle (1981) has developed such a model which proposes to examine the impact of children's development and their institutions on parents' individual life cycles at different family career stages. Rather than assuming normative childbearing patterns and adult development, Suelzle's design accounts for variations in childbearing timetables of adults--that is, adults who have children either earlier, later or on the same time schedule that current adult development theories propose (see Aldous, 1978).

Another caution for further research would be the need to study concurrently the family adaptations of parents with "normal" children and parents with children who have other disabilities (such as sick children [Burton, 1975; Travis, 1976], mentally ill children [Park and Shapiro, 1976; Shepherd, Oppenheim and Mitchel, 1966] and children with physical handicaps [McMichael, 1971; Ayrault, 1971]). It seems plausible that Farber's theory of family adaptation could be applied to all families who have children with chronically disabling conditions, not just families with severely mentally retarded children.

A hypothesis proposed, and not supported, that communities are entities that can provide therapeutic support for families should be challenged. Studies in social psychiatric epidemiology (see Levy and

Rowitz, 1973) show that communities vary in the types of support they provide their members. A more sophisticated measure of community support (perhaps involving service utilization data) is needed.

B. Implications for Planning Services

One explicit purpose of this study was to provide service providers and consumer groups with one carefully developed research base to use in planning services for mentally retarded adults. It is realized that planning in the early 1980's must take into consideration the current "tax-cutting" mood of the nation. Since present national priorities are focused on curbing government spending, increasing defense spending and developing domestic energy resources, human services in general are left trying to contend with constant or slightly rising expectations and constrained or reduced budgets.

Services to persons with mental retardation face budgetary cutbacks if not complete cancellation. "Mainstreaming" in school institutions and "deinstitutionalization" in residential institutions continue to be the policies implemented at local, state, and federal levels, though movement is afoot to end the federal mandate for tax-supported special education (P.L. 94-142). Planning of residential and vocational services for mentally retarded adults within the political climate should take into consideration parents' opinions and service choices.

Novak (1980) reports on several studies which show a backlash to the deinstitutionalization movement on the part of parents of mentally retarded children. In the present study deinstitutionalization is perceived as the application of the normalization principle in

residential services and mainstreaming, in schools. Parents who were less likely to favor mainstreaming principles were significantly older, reported experiencing more stress due to having mentally retarded children at home, and felt their community would be less accepting of their children. Their children were more likely to be older, female, and have lower cognitive and social skills. It is this group of older parents whose daughters are nearing adulthood and generally functioning at lower levels of social and cognitive development who are more likely to oppose mainstreaming.

Opposition to mainstreaming policies reflects parents' latent long-range planning. The group of parents who have made specific plans for residential placement of their mentally retarded children have some similar characteristics with the group of parents who are more likely to oppose mainstreaming. These parents are more likely to be white, reporting more stress due to having a mentally retarded child at home, feel their community would be less accepting of their children, and to have personal and community support networks. Their children tend to be older, female, and to have lower social skills.

The backlash against the deinstitutionalization and mainstreaming policies is coming from a small but significant group of parents whose children are more likely to have the severest disabilities. This should not be interpreted as an argument for ending the implementation of these policies, but a realization that the provision of a full range of services is necessary to accommodate the broad range of persons who carry the label "mental retardation."

Planners and consumer groups should also realize that the present

push for the use of mutual aid self-help groups as alternatives to the public provision of public services could be disastrous. This study has shown that personal and community support networks (which include self-help groups for parents of mentally retarded children) provide informational, not therapeutic support. Therefore, the development of self-help groups should occur in tandem with, not instead of, the provision of a full range of services.

BIBLIOGRAPHY

Abramowicz, H. K., and Richardson, S. A.: Epidemiology of severe mental retardation in children: community studies. American Journal of Mental Deficiency 80:18-39, 1975.

Adams, M.: Mental retardation and its social dimensions. New York, Columbia University Press, 1971.

Adams, M.: Social work in the community. In The mentally subnormal: social work approaches, Second edition, eds. M. Adams and H. Lovejoy, pp. 85-154. London, Heineman Medical, 1972.

Aiken, M., Dewar, R., DiTomaso, N., Hage, J., and Zeitz, G.: Coordinating human services: new strategies for building service delivery systems, First edition. San Francisco, Jossey-Bass, 1975.

Albrecht, G. L.: Social policy and the management of human resources. In The sociology of physical disability and rehabilitation, ed. G. L. Albrecht, pp. 257-288. Pittsburgh, University of Pittsburgh Press, 1976.

Aldous, J.: Family careers: developmental changes in families. New York, John Wiley, 1978.

Ayrault, E. W.: Helping the handicapped teenager mature. New York, Association, 1971.

Baller, W. R., Charles, D. C., and Miller, E. L.: Mid-life attainment of the mentally retarded: a longitudinal study. Genetic Psychology Monographs 75:235-329, 1967.

Bardwell, A.S.: Parents as partners in prevention. In Proceedings of the seminar on preventing mental retardation and developmental disabilities, pp. 31-33. Columbus, Ohio, Nisonger Center, 1976.

Baroff, G. S.: Mental retardation: nature, cause and management. Washington, D.C., Hemisphere, 1974.

Bayley, M.: Mental handicap and community care: a study of mentally handicapped people in Sheffield. Boston, Routeledge and Kegan Paul, 1973.

Begab, M. J.: The mentally retarded and society: trends and issues. In The mentally retarded and society; a social science perspective, eds. M. J. Begab and S. A. Richardson, pp. 3-32. Baltimore, University Park Press, 1975.

Biklen, D.: Let our children go: an organizing manual for advocates and parents. Syracuse, New York, Human Policy Press, 1974.

Birenbaum, A.: The mentally retarded child in the home and family life cycle. Journal of Health and Social Behavior 12:55-65, 1971.

Birenbaum, A., and Seiffer, S.: Resettling retarded adults in a managed community. New York, Praeger, 1976.

Birenbaum, A., and Re, M. A.: Resettling mentally retarded adults in the community--almost four years later. American Journal of Mental Deficiency 83:323-329, 1979.

Blatt, B.: A drastically different analysis. Mental Retardation 17: 303-306, 1979.

Brolin, D. E.: Vocational preparation of retarded citizens. Columbus, Ohio, Merrill, 1976.

Burton, L.: The family life of sick children: a study of families coping with chronic childhood diseases. Boston, Routeledge and Kegan Paul, 1975.

Burton, T. A.: The trainably mentally retarded. Columbus, Ohio, Merrill, 1976.

Carver, J. N., and Carver, N. E.: The family of the retarded child. Syracuse, New York, Human Policy Press, 1972.

Childs, R. E.: A drastic change in curriculum for the educable mentally child. Mental Retardation 17:299-301, 1979a.

Childs, R. E.: Rebuttal. Mental Retardation 17:306, 1979b.

Chinn, P. C., Drew, C. J., and Logan, D. R.: Mental retardation: a life cycle approach, Second edition. Saint Louis, C. V. Mosby, 1979.

Cobb, H. V.: The forecast of fulfillment; a review of research on predictive assessment of the adult retarded for social and vocational adjustments. New York, Teachers College Press, 1972.

Copeland, S., Addison, M., McCann, B.: Avenues to change, Books I-IV. Dallas, Association for Retarded Citizens, 1974.

Dempsey, J. J.: Community services for retarded children: the consumer-provider relationship. Baltimore, University Park Press, 1975.

DeZutter, H.: The citizen as client: have we become dependent on dependency? Reader (Chicago) 10 October 1980.

DuRand, L., and DuRand, J.: The affirmative industry. Saint Paul, Minnesota Diversified Industries, 1978.

Duvall, E. M., and Hill, R.: Report to the committee on the dynamics of family interaction. Prepared at the request of the National Conference on Family Life, Washington, D.C., 1948.

Edgerton, R. B.: The cloak of competence; stigma in the lives of the mentally retarded. Berkeley, California, University of California Press, 1967.

Edgerton, R. B., and Bercovici, S.: The cloak of competence--years later. American Journal of Mental Deficiency 80:485-497, 1976.

Edmonson, B., McCombs, K., and Wish, J.: What retarded adults believe about sex. American Journal of Mental Deficiency 84:11-18, 1979.

Elder, G. H. J.: Age differentiation and the life course. In Annual review of sociology 1, eds. A. Inkeles, J. Coleman, and N. Smelser, pp. 165-190, 1975.

Erikson, E. H.: Childhood and society, Second edition. New York, W. W. Norton, 1963.

Etzioni, A., and Richardson, S. A.: Guided societal change and mental retardation. In The mentally retarded and society; a social science perspective, eds. M. J. Begab and S. A. Richardson, pp. 469-479. Baltimore, University Park Press, 1975.

Falck, V.: Issues in planning future programs for parents of handicapped children. In Professional approaches with parents of handicapped children, ed. E. J. Webster, pp. 230-253. Springfield, Illinois, Thomas, 1976.

Farber, B.: Mental retardation and its social consequences. Boston, Houghton Mifflin, 1968.

Farber, B.: Family adaptations to severely mentally retarded children. In The mentally retarded and society; a social science perspective, eds. M. J. Begab and S. A. Richardson, pp. 247-266. Baltimore, University Park Press, 1975.

Felicetti, D. A.: Mental health and retardation politics: the mind lobbies in Congress. New York, Praeger, 1975.

Fitzgerald, H. E., Strommer, E. A., and McKinney, J. P.: Developmental psychology: the infant and young child. Homewood, Illinois, Dorsey, 1977.

Fotheringham, J. B., Skelton, M., and Hoddinott, B. A.: The retarded child and his family: the effects of home and institution. Toronto, Ontario, Institute for Studies in Education, 1971.

Ginsburg, H., and Opper, S.: Piaget's theory of intellectual development: an introduction. Englewood Cliffs, New Jersey, Prentice-Hall, 1969.

Gold, M.: Vocational training. In Mental retardation and developmental disabilities, Volume VII, ed. Joseph Wortis, pp. 254-264. New York, Brunner/Mazel, 1975.

Gunn, J. E.: A consideration of some epidemiological factors in the labeling of "educable mentally retarded children." Master's thesis, School of Public Health, University of Illinois at the Medical Center, 1978.

Hall, G. S.: Adolescence. New York, D. Appleton, 1904.

Hansen, H., Belmont, L., and Stein, Z.: Epidemiology. In Mental retardation and developmental disabilities, Volume XI, ed. Joseph Wortis, pp. 178-212. New York, Brunner/Mazel, 1980.

Havighurst, R. J.: Developmental tasks and education. New York, David McKay, 1952.

Herold, D. M.: Long range planning and organizational performance: a cross validation study. Academy of Management Journal March: 91-102, 1972.

Hill, R., and Hansen, D. A.: The identification of conceptual frameworks utilized in family study. Marriage and Family Living 22: 299-311, 1960.

Hobbs, N.: The futures of children: categories, labels and their consequences. San Francisco, Jossey-Bass, 1975.

Hurley, R.: Poverty and mental retardation: a causal relationship. New York, Random House, 1969.

Hyman, H. H.: Health planning: a systematic approach. Germantown, Maryland, Aspen, 1976.

Inhelder, B.: The diagnosis of reasoning in the mentally retarded. New York, John Day, 1968.

Karnes, M. B., Zehrbach, R. R., and Teska, J. A.: Involving families of handicapped children. In Mental retardation: social and educational perspectives, eds. C. J. Drew, M. L. Hardman, and H. P. Bluhm, pp. 38-45. Saint Louis, C. V. Mosby, 1977.

Katz, A. H.: Parents of the handicapped: self-organized parents' and relatives' groups for treatment of ill and handicapped children. Springfield, Illinois, Thomas, 1961.

Katz, E.: The retarded adult in the community. Springfield, Illinois, Thomas, 1968.

Keenan, V., and Suelzle, M.: Parents--the most important members of the team of professionals working with developmentally disabled children. Unpublished, 1980.

Kurtz, R. A.: Social aspects of mental retardation. Lexington, Massachusetts, Lexington Books, 1977.

Kushlick, A.: Epidemiology and evaluation of services for the mentally handicapped. In The mentally retarded and society; a social science perspective, eds. M. J. Begab and S. A. Richardson, pp. 325-344. Baltimore, University Park Press, 1975.

Lapouse, R., and Weitzner, M.: Epidemiology. In Mental retardation Volume I, ed. J. Wortis, pp. 197-223. New York, Grune and Stratton, 1969.

Lefrancois, G. R.: Adolescents. Belmont, California, Wadsworth, 1976.

Levinson, D. J., Darrow, C. N., Klein, E. B., Levinson, M. H., and McKee, B.: The seasons of a man's life. New York, Ballantine, 1978.

Levy, L., and Rowitz, L.: The ecology of mental disorder. New York, Behavioral Publications, 1973.

MacKeith, R.: The feelings and behavior of parents of handicapped children. In The handicapped person in the community: a reader and sourcebook, eds. D. Boswell and J. M. Wingrove, pp. 127-129. London, Tavistock, 1974.

MacMillan, D. L.: Mental retardation in school and society. Boston, Little Brown, 1977.

Maloney, M. P., and Ward, M. P.: Mental retardation and modern society. New York, Oxford University Press, 1979.

Matheny, A. P., and Vernick, J.: Parents of the mentally retarded child: emotionally overwhelmed or informationally deprived? Journal of Pediatrics 74:953-959, 1969.

Mausner, J. S., and Bahn, A. K.: Epidemiology: an introductory text. Philadelphia, Saunders, 1974.

McMichael, J. K.: Handicap: a study of physically handicapped children and their families. Pittsburgh, University of Pittsburgh, 1971.

Mechanic, D.: Mental health and social policy, Second edition. Englewood Cliffs, New Jersey, Prentice-Hall, 1980.

Mercer, J. R.: Patterns of family crises related to reacceptance of the retardate. American Journal of Mental Deficiency 71:19-32, 1966.

Mercer, J. R.: Labeling the mentally retarded: clinical and social system perspective on mental retardation. Berkeley, California, University of California Press, 1973a.

Mercer, J. R.: The myth of the 3% prevalence. In Sociobehavioral studies in mental retardation, eds. R. K. Eyman, C. E. Meyers, and G. Tarjan, pp. 1-17. Washington, D.C., American Association on Mental Deficiency, 1973b.

Morgenstern, M.: The psychosexual development of the retarded. In Human sexuality and the mentally retarded, eds. F. F. de la Cruz and G. D. LaVeck, pp. 15-28. New York, Brunner/Mazel, 1973.

Nirje, B.: The normalization principle and its human management implications. In The history of mental retardation, Volume 2, eds. M. Rosen, G. R. Clark, and M. S. Kivitz, pp. 361-370. Baltimore, University Park Press, 1976.

Novak, A. R.: Backlash to deinstitutionalization movement. In Integration of developmentally disabled individuals into the community, eds. A. R. Novak and L. W. Heal, pp. 181-192. Baltimore, Brookes, 1980.

Oppenheimer, V. C.: The life cycle squeeze: the interaction of men's occupational and family life cycles. Demography 11:227-245, 1974.

Paluszny, M. J.: Autism: a practical guide for parents and professionals. Syracuse, New York, Syracuse University Press, 1979.

Park, C. C., and Shapiro, C. C.: You are not alone. Boston, Little Brown, 1976.

Paul, J. L.: The need for advocacy. In Child advocacy within the system, eds. J. L. Paul, G. R. Neufeld, and J. W. Pelosi, pp. 1-10. Syracuse, New York, Syracuse University Press, 1977.

Paul, J. L., Turnbull, A. P., and Cruickshank, W. M.: Mainstreaming: a practical guide. Syracuse, New York, Syracuse University Press, 1977.

Pelosi, J. W.: Advocacy system: generic components. In Child advocacy within the system, eds. J. L. Paul, G. R. Neufeld, J. W. Pelosi, pp. 32-40. Syracuse, New York, Syracuse University Press, 1977.

Perske, R.: The dignity of risk and the mentally retarded. Mental Retardation 10:24-26, 1972.

Piaget, J.: Intellectual evolution from adolescence to adulthood. Human Development 15:1-12, 1972.

Plato: The Republic, Second edition (revised). Translated by D. Lee. Baltimore, Penguin, 1974.

Robbins, S. P.: The administrative process: integrating theory and practice. Englewood Cliffs, New Jersey, Prentice-Hall, 1976.

Robinson, N. M. and Robinson, H. B.: The mentally retarded child: a psychological approach, Second edition. New York, McGraw-Hill, 1976.

Rosow, I.: Socialization to old age. Berkeley, California, University of California Press, 1974.

Rowitz, L.: Social factors in mental retardation. Social Science and Medicine 8:405-412, 1974.

Rowitz, L.: Social problems in transition. In Transition: preparation of the developmentally disabled for adult life. Chicago, Illinois, Illinois Institute for Developmental Disabilities, 1975.

Rutter, M. L.: Psychiatry. In Mental retardation, Volume III, ed. J. Wortis, pp. 207-208. New York, Grune and Stratton, 1971.

Scheerenberger, R. C.: Deinstitutionalization and institutional reform. Springfield, Illinois, Thomas, 1976.

Schopler, E.: Towards reducing behavior problems in autistic children. In Early childhood autism: clinical, educational, and social aspects, ed. Lorna Wing, pp. 238-241. New York, Pergamon, 1976.

Schwartz, C. G.: Strategies and tactics of mothers of mentally retarded children for dealing with the medical care system. In Diminished people, problems and care of the mentally retarded, ed. N. R. Bernstein, pp. 73-105. Boston, Little Brown, 1970.

Sellin, D. F.: Mental retardation: nature, needs and advocacy. Boston, Allyn and Bacon, 1979.

Shepherd, M., Oppenheim, A. N., and Mitchel, S.: Childhood behavior disorders and child-guidance clinic: an epidemiological study. Journal of Child Psychology and Psychiatry 7:39-52, 1966.

Stein, Z., and Susser, M.: Public health and mental retardation: new power and new problems. In The mentally retarded and society; a social science perspective, eds. M. J. Begab and S. A. Richardson, pp. 53-73. Baltimore, University Park Press, 1975.

Sternlicht, M., and Deutsch, M. R.: Personality development and social behavior in the mentally retarded. Lexington, Massachusetts, D. C. Heath, 1972.

Suelzle, M.: A proposal to design and pretest a study of childbearing timetables on adult development. Unpublished, 1981.

Suelzle, M., and Keenan, V.: The world of the developmentally disabled child. Evanston, Illinois, Northwestern University, 1979.

Suelzle, M., and Keenan, V.: Parents as advocates for handicapped children: untapped resources for social change in the 1980's. Unpublished, 1980.

Thune, S. S., and House, R. J.: Where long-range planning pays off. Business Horizons August:81-87, 1970.

Tizard, J., and Grad, J. C.: The mentally handicapped and their families: a social survey. London, Oxford University Press, 1961.

Travis, G.: Chronic illness in children: its impact on child and family. Stanford, California, Stanford University Press, 1976.

Vaillant, G.: Adaptation to life. Boston, Little Brown, 1977.

Warren, S. A.: What is wrong with mainstreaming? A comment on drastic change. Mental Retardation 17:301-303, 1979.

Winch, R. F.: The modern family, Third edition. New York, Holt, Rinehart and Winston, 1971.

Wing, J. K., and Olson, R.: Principles of the new community care. In Community care for the mentally disabled, eds. J. K. Wing and R. Olson, pp. 171-185. New York, Oxford University Press, 1979.

Wing, L., and Gold, J.: Caring for the mentally retarded. In Community care for the mentally disabled, eds. J. K. Wing and R. Olson, pp. 106-131. New York, Oxford University Press, 1979.

Wolfensberger, W.: The three stages in the evolution of voluntary associations for retarded persons. Mental Retardation News 22: 2, 1973.

VITA

Name: Vincent D. Keenan

Date of Birth: June 30, 1956

Place of Birth: Chicago Heights, Illinois

Education: Master of Science in Public Health Sciences, 1981
University of Illinois at the Medical Center
Chicago, Illinois

Bachelor of Science in Education, 1978
Northwestern University
Evanston, Illinois

Honors: United States Public Health Traineeship, 1979-1981

Employment: Staff Intern, 1981
Illinois Commission on Mental Health and Developmental Disabilities
Chicago, Illinois

Research Associate, 1980-1981
Hospital Research Center, American Hospital Association
Chicago, Illinois

Research Assistant, 1980
Center for Urban Affairs, Northwestern University
Evanston, Illinois

Project Coordinator, Developmental Disabilities Project, 1978-1979
Center for Urban Affairs, Northwestern University
Evanston, Illinois

Publications:

Suelzle, M., and Keenan, V.: Changes in family support networks over the life cycle from preschool to young adulthood. American Journal of Mental Deficiency, Forthcoming.

Suelzle, M., and Keenan, V.: El mundo del nino con trastornos del desarrollo. Traducio y adaptado al espanol por R. Zimmerman y I. T. Zimmerman. Evanston, Illinois, Center for Urban Affairs, Forthcoming.

Suelzle, M., and Keenan, V.: Parents' choice of services for developmentally disabled children: final report. Evanston, Illinois, Center for Urban Affairs, Forthcoming.

Suelzle, M., and Keenan, V.: Technical report on a research strategy for investigating the service needs of developmentally disabled children. Evanston, Illinois, Center for Urban Affairs, 1980.

Keenan, V.: Self-help annotated bibliography. In Epilepsy self-help workbook, ed. L. Borman. Evanston, Illinois, Self-Help Center, 1980.

Keenan, V., Piekarski, J., and Kopatic, A.: Epilepsy self-help group profiles. In Epilepsy self-help workbook, ed. L. Borman. Evanston, Illinois, Self Help Center, 1980.

Suelzle, M., and Keenan, V.: The world of the developmentally disabled child. Evanston, Illinois, Center for Urban Affairs, 1979.